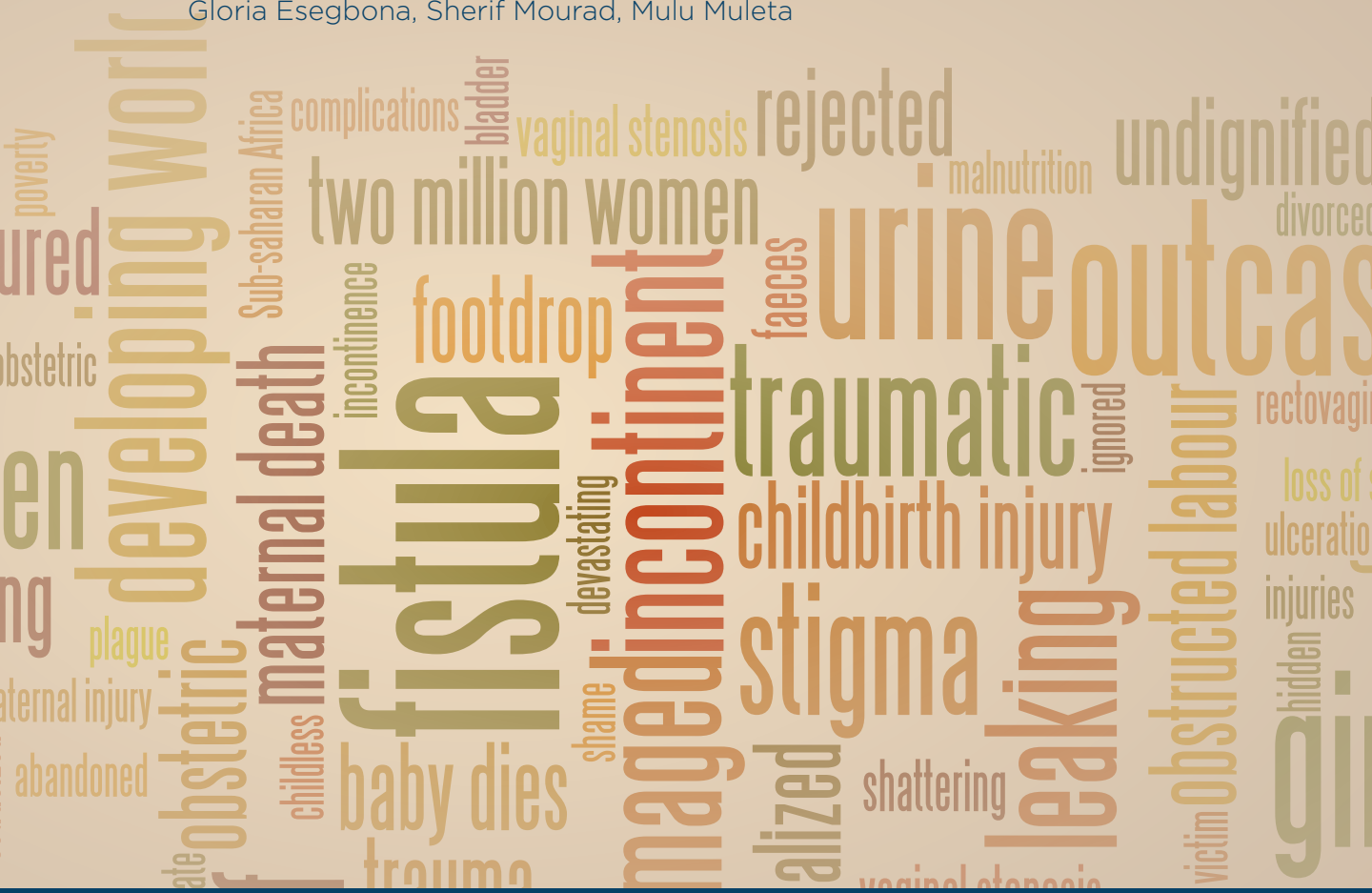


Obstetric Fistula

in the DEVELOPING WORLD

By: Paul Abrams, Dirk de Ridder, Catherine deVries, Sohier Elneil, Gloria Esegbona, Sherif Mourad, Mulu Muleta



An International Consultation on Vesicovaginal Fistula

Marrakech, Morocco, October 13-16, 2010

Co-sponsored by

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Editor

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COMMITTEE 6

DIGNITY
CHILDREN ^{SISTER} SMILE
INTERACTION ^{PRODUCTIVE} EMPOWERED ^{STATUS} ^{SOCIALISE} ^{RELATIONSHIP}
REPAIRED ^{EDUCATION} MOTHER ^{WIFE} ^{BO}
CONTINENT ^{SEXUAL LIFE} ^{DAUGHTER} ^{HEALTHY} ^{REINTEGRAT}
ALIVE ^{HOME} ^{NEW LIFE} ^{MARRI}
FAMILY ^{CONFIDENT} ^{INTO}
CURED ^{JOY} ^{SKILLED} ^{TRIUM}
STRONG ^{SUPPORTED} ^{ACCEPTED}
HAPPINESS ^{LAUGH} ^{FREE} ^{PA}
SELF ESTEEM ^{LIVING} ^{FERTILE} ^{TRA}
HUSBAND ^{PARTICIPATION}
ECONOMIC EMPOWERMENT
AGENTS OF CHANGE

Abbreviations Used in the Text

| | |
|-------|---|
| AAFH | Addis Ababa Fistula Hospital |
| Ach | acetylcholine |
| AIDS | Acquired Immune Deficiency Syndrome |
| AMREF | African Medical and Research Foundation |
| ANC | antenatal care |
| AUA | American Urological Association |
| AUGS | American Urogynecologic Society |
| BCC | Behaviour Change Communication |
| BDHFH | Bahir Dar Hamlin Fistula Hospital |
| BNO | bladder neck obstruction |
| CCBRT | Comprehensive Community Based Rehabilitation Hospitals Fistula Ward |
| CFA | community fistula advocates |
| DALY | disability-adjusted life year |
| DCP2 | Disease Control Priorities-2 |
| DHS | Demographic Health Survey |
| DMCH | Dhaka Medical College Hospital |
| DO | detrusor overactivity |

| | |
|---------|---|
| EH | EngenderHealth |
| EL | Evidence Level |
| EmOC | Emergency Obstetric Care |
| EmONC | Emergency Obstetric and neonatal care |
| FFNIG | Fistula Foundation Nigeria |
| FGC | female genital cutting |
| FGDs | focus group discussions |
| FGM/C | female genital mutilation/cutting |
| FIGO | International Federation of Gynaecology and Obstetrics |
| FORWARD | The Foundation for Women's Health, Research and Development |
| FRRC | Fistula Rehabilitation and Reintegration Center |
| GBD | Global Burden of Disease |
| GFMER | Geneva Foundation for Medical Education and Research |
| HIV | human immunodeficiency virus |
| ICS | International Continence Society |
| IEC | Information, Education and Communication |
| IGA | income-generating activities |
| IOFWG | International Obstetric Fistula Working Group (IOFWG) |
| ISOFS | International Society of Obstetric Fistula Surgeons |
| IUGA | International Urogynecological Association |

| | |
|-------|--|
| KDH | Kissidougou District Hospital |
| MCH | Maternal Child Health |
| MDG5 | Millennium Development Goal 5 |
| MISP | Minimum Initial Service Package |
| MSF | Médecins Sans Frontières/Doctors Without Borders |
| NGO | non-governmental organization |
| OAB | overactive bladder |
| PAUSA | Pan-African Urological Surgeons Association |
| PBA | performance-based assessment |
| PCN | percutaneous nephrostolithotomy |
| PQoL | perceived quality of life |
| PROM | premature rupture of membranes |
| QOL | quality of life |
| RAI | rural access index |
| RCOG | Royal College of Obstetricians and Gynaecologists |
| RCT | randomized controlled trial |
| REF | Réseau Pour l'Élimination de la Fistule Obstétricale |
| RVF | rectovaginal fistula |
| SBAs | skilled birth attendants |
| SGS | Society of Gynecologic Surgeons |

| | |
|---------|--|
| SIU | Société Internationale d'Urologie |
| SMoWASD | The State Ministries of Women's Affairs and Social Development |
| SUI | stress urinary incontinence |
| TBA | traditional birth attendant |
| UDC | The Urban Development Commune |
| UNFPA | United Nations Population Fund |
| USI | urinary stress incontinence |
| UTI | urinary tract infection |
| UVF | urethrovaginal fistula |
| VVF | vesicovaginal fistula |
| WAHA | Women and Health Alliance International |
| WHO | World Health Organization |

Foreword



**Serigne Magueye Gueye,
MD, FWACS**

Professor of Urology and
Fistula Surgeon
Cheikh Anta Diop University
Head of Urology, Grand Yoff
General Hospital

It is globally accepted that for each maternal death, 20 women experience serious complications related to pregnancy. Obstetric fistula secondary to obstructed and prolonged labour is one of the most devastating maternal morbidities.

Though there are only scant data on the global epidemiology of vesicovaginal fistula (VVF), it is thought that 80% of fistula patients live in sub-Saharan Africa. The holistic approach toward elimination of obstetric fistula includes prevention, repair of existing fistula cases, and social reintegration.

The first Société Internationale d'Urologie-International Consultation on Urological Diseases (SIU-ICUD) Consultation on VVF is timely, as it occurs at the moment when a group of fistula experts, organized around the International Federation of Gynaecology and Obstetrics (FIGO) and partners, releases the first-ever consensual Global Competency-Based Fistula Surgery Training Manual.

This first Consultation, consistent with the tradition of ICUD, gathered world experts to address key issues on VVF as regards epidemiology, prevention, treatment, complications, and social reintegration.

This book is an opportunity for fistula surgeons and fistula care providers worldwide to access evidence-based information on VVF that will benefit patients suffering from fistula.

I would like to express my deep gratitude to the ICUD for assigning us this exciting task, as well as to the SIU for supporting this great initiative. I wish to thank all the SIU-ICUD Consultation on VVF committee members for sharing their experience, and for the valuable time and effort donated to achieve our objective.

Special thanks to Professor Paul Abrams for ably coordinating this effort.

Serigne Magueye Gueye, MD, FWACS

Honorary Chair, First SIU-ICUD Consultation on Vesicovaginal Fistula
President of PAUSA
Member, SIU Nominating Committee
Dakar, Senegal

mother normal healthy
living new life self esteem
adapted
alive dignity better life
children sister participation socialise
relationships supported training
triumph empowered
confident home productive
wife husband daughter Cont
interaction Cured

Preface



Paul Abrams, MD
Professor of Urology,
University of Bristol, UK

International Consultation on Vesicovaginal Fistula 2010

The development of a fistula is a devastating event for any woman. However, if this occurs when there is little hope of effective treatment, then the results are even more horrendous with profound effects on all aspects of the woman's life.

Most fistulas occur in the developing world and result from obstructed labour and failure to provide the basic obstetric care, which is taken for granted in the developed world. A vesicovaginal fistula (VVF) is the most common form, but rectovaginal fistula and more complex fistula are also common. It is estimated that there are two million women suffering from untreated fistula in the developing world, mainly in sub-Saharan Africa, India and South East Asia.

The fistula surgeons gathered for the 1st International Consultation on Vesicovaginal Fistula, in Marrakech, in October 2010, under the joint auspices of the International Consultation on Urological Diseases (ICUD) and the Société Internationale d'Urologie (SIU). This book, entitled *Obstetric Fistula in the Developing World*, represents a milestone in the documentation of the evidence about VVF. By comprehensively reviewing the scientific literature, and assessing its quality, the Consultation has laid the foundations for future clinical and research work, aimed at reversing the terrible tide of this condition.

The six chapters provide a comprehensive picture of the situation. However, the efforts of the committees were limited by the quality of the evidence. There is no Level 1 evidence, as there are no randomized controlled trials. Almost all evidence comes in the form of case series and observational data. Nevertheless, the committees have summarized the data, highlighting those recommendations that they were able to make and emphasizing the importance of the need for high quality research to ensure that women who suffer VVF are treated in the optimal manner.

The surgical management of VVF must be optimized, and the techniques used should be developed by comparing the outcomes between procedures. However, no proper research can be performed without a common language to describe the woman's pre-operative fistula and the results of fistula surgery. Therefore, one of the most important decisions made by the Consultation was to recommend one system of classification for fistula. It was decided to recommend the Waaldijk Classification as this had been used to assess outcome from fistula surgery in the largest number of women.

Evidence is presented as to how the Waaldijk Classification predicts outcome following surgery. Inevitably there will be some disquiet that the Waaldijk Classification has been chosen, rather than one of the other 30 classifications that exist. However, the Consultation's decision is a wise and brave one, as it is vital that the various surgical developments can be compared one with another. Without a common way of describing the fistula, that is, a single agreed classification, it would be impossible to compare one technique with another, and consequently the speed of improvement in fistula surgery would be slowed. There will be the opportunity to review the recommended classifications and, should a superior classification (as shown by its proper validation and its relation to outcome) be developed, then that classification, after comparison with the Waaldijk Classification, would be adopted by the scientific community.

Although a lot of the available data refers to surgical results, the book emphasizes that a significant minority of VVF can be effectively treated by urethral catheterization, if the woman comes to the attention of trained nursing or medical staff at the time of obstructed labour or shortly after. Hence a protocol for urethral catheterization, on free urine drainage, is mandatory for women who present early. Adoption of such a simple measure would probably reduce the incidence of VVF by one-quarter

Sadly, the number of untreated VVFs is increasing because the surgical capacity to keep pace with new cases that develop each year is inadequate. Therefore, the long-term solution to the problem is prevention. Fortunately there is some descriptive evidence of relatively simple measures that can make a huge difference in reducing the occurrence of VVF. But, in the meantime, there must be continued efforts to treat those women who have established fistula.

There are important partners supporting fistula surgeons, namely the non-governmental organizations (NGOs) such as WHO, UNFPA and MSF. The cooperation between the NGOs and the surgeons is vital, as the NGOs bring much-needed financial and logistic support. Also important are the efforts of professional organizations. The International Society of Fistula Surgeons (ISOFS) was founded in 2007 and is therefore a relatively new society. However it enjoyed a most successful meeting in Dakar, Senegal, in December 2010, under the chairmanship of its President, Dr. Kees Waaldijk, and the President of the Pan-African Urological Surgeons Associations, Professor Serigne Gueye. The International Society of Fistula Surgeons has worked closely with the International Federation of Gynaecology and Obstetrics (FIGO), who have produced a training handbook which aims to ensure that only properly trained surgeons operate on women with VVF.

This is another essential piece in the jigsaw puzzle of the prevention and management of VVF. Also noteworthy is the recent announcement of joint funding by the American Urological Association, the European Association of Urology and the SIU to support the development of surgery, including fistula surgery in the developing world.

Finally, it was a huge personal privilege to have been able to organize this consultation for the fistula surgeons. They are a remarkable group of men and women who dedicate their lives to helping women with this dreadful condition.

Paul Abrams, MD

Chairman of the International Consultation on Urological Diseases

new life living job
reintegration husband education
agents of change repaired
healthy daughter joy relationships
happiness triumph better life
economic empowerment sexual life wife
intercourse
productive marriage normal
isofs home accepted smile
confident
free CONTINENT
status proud dignity skilled
strong family sister
laugh interaction empowered
training participation socialise mother
self esteem children supported
cured alive

Recommendations of the International Scientific Committee

Paul Abrams, Dirk de Ridder, Catherine deVries, Sohier Elneil, Alice Emasu, Gloria Esegbono, Serigne Gueye, Sherif Mourad, Mulu Muleta and the members of the committees.

I. Introduction

The First ICUD-SIU Consultation on Vesicovaginal Fistula (VVF) was held at the SIU meeting in Marrakech, Morocco, October 13th – 16th 2010. The recommendations are evidence-based, following a thorough review of the available literature and the opinion of recognized experts serving on the six committees. The individual committee reports were developed and peer-reviewed by open presentation and comment. Review of the literature showed no Level 1 evidence in that there were no randomized controlled trials. All evidence was confined to case series and observational data: Level 3 and 4 evidence. Hence, all recommendations were Grades B and C.

The Scientific Committee includes the chairmen of the six committees, who refined the final recommendations. These recommendations, published in 2011, will be periodically re-evaluated in the light of clinical experience, technological progress and research. These recommendations are taken from the full versions of the six Consultation chapters, from Epidemiology through to Social Reintegration. These chapters provide the full documentation of the existing scientific literature on the six topic areas.

II. Women, Fistula Surgeons, Non-Governmental Organizations and Governments

The effect on a woman, in the developing world, of having a VVF resulting from obstructed labour, is disastrous from her point of view, the family perspective and for her society. It is estimated that there are two million women, in developing countries, mainly in sub-Saharan Africa, the Indian sub-continent and South-East Asia, who have either undetected or untreated VVFs. New fistulas are probably occurring at the rate of 82,000 new cases per year, yet only 10,000 operations for fistula closure are being done annually. Hence, this leaves a huge unmet need.

Vesicovaginal fistula, in itself, is bad enough, but it is also inextricably linked with high maternal mortality rate and high infant death rate. Hence, the solution to fistula is similar to the solutions that will drive down the maternal mortality rate and the infant death rate. The solutions are not only medical, but also social and political in nature.

At present, women in developing countries are often dependent on donations that reach their country through non-governmental organizations (NGOs) and charities. The relationship between the NGOs and the fistula surgeons are critical. The fistula surgeons are the experts and those to whom fistula women turn for help. Hence, it is vital that the NGOs allow themselves to be guided by the fistula surgeons as to the priorities within their sphere of work. The vital role of the NGOs is to provide financial and logistical support. Support is also essential to allow the fistula surgeons to write up their work. This is often a considerable problem, as their

commitment to the women means that their academic time is restricted. Nevertheless, the data the fistula surgeons generate is their intellectual property, and it is vital that they retain primary authorship of all published material.

There are an enormous number of committed and dedicated individuals from both within the developing countries and from developed countries who have committed themselves to the cause of helping women with this dreadful condition. However, the long-term solution must see the responsibilities for women's and children's health passing to the governments of the individual countries. Nevertheless, in the meantime, those many dedicated individuals will continue to strive to help as many women as possible return to a life in their own community.

III. Epidemiology of Vesicovaginal Fistula

Epidemiological studies on obstetric fistula are inadequate:

- They are mainly institutionally-based, retrospective case series, often written from the perspective of a single fistula surgeon.
- The geographical coverage of epidemiological reports is uneven.
- However, better and more relevant information is emerging.

The incidence of fistula is expressed per 1,000 deliveries and would appear to be between 0.1% rising to 1.5 per 1,000 pregnancies in rural areas.

The major risk factors appear to be age at first marriage, short stature, pregnancy with a male child rather than a female child, failure to attend antenatal care, low socio-economic status, low social class, lack of employment, and illiteracy.

The consequences of obstetric fistula include divorce (16-92%), social isolation, worsening poverty, malnutrition, sexual dysfunction, mental illness (including anxiety/depression), insomnia, general ill health, and thoughts of worthlessness and suicide.

There are few detailed reports documenting these women's obstructed labours. The time of onset of labour is rarely recorded and reports from delivery locations may disregard the fact that the woman has laboured at home for days prior to reaching the delivery location. The reason for the woman not receiving help rarely differentiates between the absence of health-seeking behaviour and the lack of services. The only observational study showed no substantial difference between VVF patients and women who delivered without fistula, both in terms of their use of orthodox health care services and more traditional forms of support before childbirth.

Recommendations

1. Community-based epidemiological studies using standardized and validated collection tools with acceptable sensitivity and specificity are highly recommended.
 2. A validated standardized collection tool should be developed and used in national surveys to facilitate the collection and comparison of data when assessing the regional, continental and global magnitude of VVF, and the distribution of fistula worldwide.
 3. Prospective longitudinal community-based studies are needed to estimate the incidence of obstetric fistula.
 4. Observational studies are needed utilizing advanced epidemiological analyses for:
 - Risk factors (multivariate analysis controlling potential biases)
 - Impacts and consequences of VVF
 - Determining health-seeking behaviour
 5. Research that identifies the different profiles of women who manage to overcome the obstacles and successfully access health care compared to those who do not is recommended.
 6. The contribution of other factors such as ethnic background and malnutrition needs to be researched and understood.
 7. It is recommended that there be long-term follow up of patients following fistula repair to understand their ongoing quality of life and any long-term sequelae and ongoing needs.
-

IV. Prevention of Vesicovaginal Fistula

Vesicovaginal fistula is a characteristic of abject poverty, a clear marker of failure of political, social and health systems to protect and promote women's health and their rights. Prevention of VVF is ultimately linked to prevention of maternal and infant mortality and is a requirement of the Millennium Development Goal 5 (MDG5) of 2000.

Prevention, from the medical and public health point of view, mitigates the effect of VVF in the overall burden of pain and suffering the condition imposes, not just on the patient herself, but on her family and on the entire community. History has shown that improvements in the functioning of local health services dramatically reduce the incidence of maternal death, infant mortality and VVF. The following areas of health system improvement and capacity building need to be considered:

- Enhancing professionalism among health care workers to make the system work better.
- Massive infrastructural developments through strengthening existing government health facilities, and advocacy, to maximize the benefits that a political environment sensitive to the needs of these women is required.
- Ensuring that facilities are properly equipped, monitored, and supervised, with an emphasis on quality as well as quantity of service provision.

Systematic improvements are required to address the social and economic inequalities, such as the low status of women, lack of education for girls, early marriages and pregnancy, malnutrition, poverty, inadequate health and transportation infrastructure, and harmful traditional practices, such as female genital mutilation.

Health and maternal care are inextricably linked to the availability of financial resources, to the individual in the community and within the country as a whole: as economic conditions improve, the risk of VVF diminishes.

Another key strategy in preventing VVF is the empowerment of women and their spouses, to develop birth preparedness plans within the context of family planning. Family planning in wealthy regions is available according to the choice of the individual, whilst in other developing areas, such as China, it is actively encouraged, or even enforced. Other components of public health care, such as addressing the special nutritional needs of female children and the requirements of improving their physical health, in order to improve their physical growth and maturity, are also very important.

Education of the community is vital so that young women understand what VVF is, are made aware of the need to engage in the antenatal care process, and plan for their delivery, including making transportation plans for use when they go into labour.

Prevention strategies can be considered in public health terms as primary, secondary or tertiary:

- Primary prevention addresses many of the indirect causes which are essential root causes of fistula. It attempts to reduce or eliminate the risk of the disease and by, amongst other actions, reducing the high levels of illiteracy among women. It also seeks to widen the cadre of care workers by involving, for instance, traditional birth attendants (TBA).
- Secondary prevention attempts to limit the severity of the disease by detecting it at its earliest stages.
- Tertiary prevention aims to mitigate the effects of the existing disease, for example by effective treatment.

The work of Haddon and Maine in the Haddon Matrix and Maine’s Three Delays provide documented approaches to the problems.

TABLE 1 Categories of Prevention Strategies: The Haddon Matrix

| Primary Prevention | Secondary Prevention | Tertiary Prevention |
|--|---|---|
| <ul style="list-style-type: none"> ■ Nutrition ■ Education of female child and engagement of TBAs ■ Delayed marriage ■ Training of medical staff/midwives ■ Roads, ambulance, functioning health facilities ■ Communication ■ Adequate facilities, equipment and staff ■ Electricity | <ul style="list-style-type: none"> ■ Transportation ■ Maternity waiting houses ■ Field surveys ■ Partographs ■ Low gynecological age ■ Caesarean section (symphysiotomy) ■ Foley catheter drainage | <ul style="list-style-type: none"> ■ Treatment/repairs (surgery) ■ Physical/social/economic rehabilitation and reintegration ■ Media campaigns |

Maine's Three Delays

The first delay The decision to seek care is influenced by the socio-economic and cultural factors in that woman's environment. These can include the need to obtain permission from a husband or male family member to seek care, or the community perception that only weak women need assistance with delivery and that strong women can manage delivery on their own.

The second delay The delayed arrival at the health facility. Once the first delay has occurred, the second delay becomes more serious. Road conditions, transportation and communication deficiencies may conspire to delay the woman's arrival at a hospital or birthing centre.

The third delay The delayed provisions of adequate care at the facility may be due to lack of staff, supplies, or electricity. If the lights are out and there is no back-up generator or fuel, a caesarean section cannot be done. If there is no way to reach a doctor or medical officer because there are no telephones, or if equipment hasn't been sterilised, then timely surgery cannot be performed. These three stages of delay disproportionately affect the world's poor and, in particular, those women living in rural areas.

Recommendations

1. Strong community support is required to develop solidarity groups which include village volunteers working with trained, skilled and traditional birth attendants, depending on the local customs and resources.
 2. The components of the three delays need to be identified and targeted in order to minimize the effect of obstructed labour. By this process, there will be other benefits for maternal and child health.
 3. There should be provision of adequate health facilities and birthing centres to which women move, either as soon as they go into labour, or if labour is delayed. Such facilities must provide emergency obstetric care, including caesarean section.
 4. National policies for maternity care should be developed for all countries whether or not VVF is a common complication of childbirth.
 5. Data collection by local, national and regional bodies should help to define the incidence of birth complications, and factors leading to the "Three Delays".
 6. The components of the "Three Delays" need to be identified and targeted for each community where there is a high prevalence of complications of childbirth.
 7. Girls, women and communities should be educated about normal and abnormal labour, and facilities, such as waiting houses, should be available for pregnant women at risk for complicated deliveries.
 8. Solidarity groups including local volunteers, as well as skilled and trained traditional birth attendants should be developed for maternal care.
 9. Birthing centres with the capability for caesarean section should be accessible and sufficiently affordable for women to use.
 10. Funding should be made available to retain adequate trained staff for waiting houses and birthing centres.
 11. Partographs should be employed to track the progress of delivery in order to identify problems and for data collection.
-

V. Unmet Needs in Vesicovaginal Fistula

There is unmet need at every level of the health care service in those developing countries where VVF is a significant problem. These needs span from family planning through obstetric care, the availability of emergency obstetric services, and the provision for dealing with maternal and infant postpartum problems.

Unmet need has not clearly been defined, although the increasing gulf between the prevalence and incidence of fistula and its prevention and treatment is exceedingly worrying.

In low-resource countries, there is a need for stable and enduring collaboration and partnerships between governments and NGOs, such as the United Nations Population Fund (UNFPA), EngenderHealth (EH) the World Health Organization (WHO) and Médecins Sans Frontières (MSF). These partnerships are vital to identifying unmet needs and ensuring that these are reduced.

One of the most important aspects of the unmet needs in fistula surgery training has been the lack of standardization. In order that the recommendations below can even be partially met, there has to be a global strategy in developing training, education, and ancillary support for the surgeons and their associated teams. This will be partially met by the creation of the global competency-based fistula surgical training manual, created by the International Federation for Gynaecology and Obstetrics (FIGO) in collaboration with fistula surgeons, professional organizations and specialist health organizations. The purpose of this manual is to enable health care providers to acquire the required knowledge, skill and professionalism to prevent fistula and provide holistic care to fistula patients that includes medical, psychosocial and surgical care. A multidisciplinary team-based approach is encouraged in the training of each doctor and his/her team nurses, physiotherapists and other health professionals. The course is structured at three levels: standard, advanced and expert levels of fistula training.

The manual is made up of several components:

Curriculum Modules

Each module has an outline of the course content that the trainee is expected to be aware of. It needs to be used in conjunction with recommended references, and in some cases, with specific Performance Based Assessments (PBAs). There are seven modules that need to be undertaken.

Logbooks of Competency

These are records of the work carried out by each trainee. Each must be signed off by each trainer, who will determine if the trainee has observed a procedure, has assisted with a procedure, or is able to work independently. The trainer will determine if the trainee requires further training in a particular area.

Performance Based Assessment (PBA)

Each aspect of surgical training will be assessed separately and specifically. The trainees will complete each PBA to a standard, advanced or expert level and ideally need the signature of two or more trainers, from two or more training centres. It is expected that each trainee will undergo a prolonged period of fistula training at one or more centres. There are 15 PBAs to be completed before a fistula surgeon is deemed an expert, and will often require the full 24 months of training. However, this is a competency-based training manual and each trainee will require different lengths of time to achieve each level of expertise.

This structured approach of the competency-based manual will attempt to standardize and support surgical training in fistula repair. In the process of achieving this aim, it is envisaged that there will eventually be an increase in the number of training centres accredited for training and eventually, surgeons trained.

Recommendations

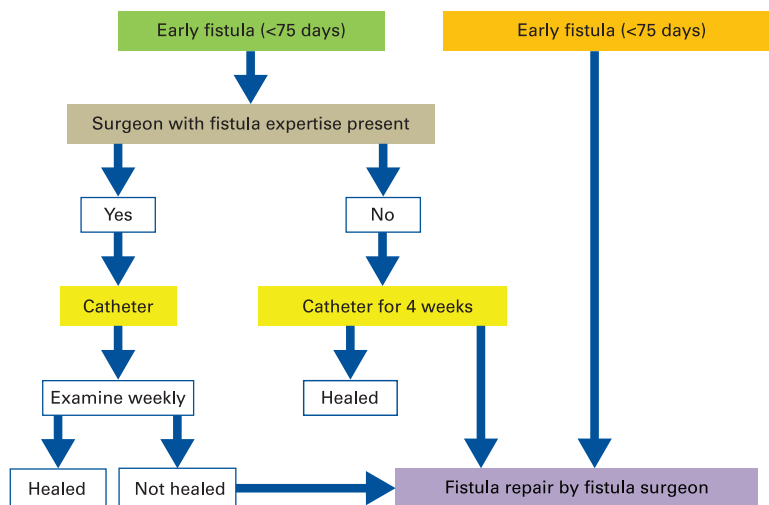
1. Unmet need has to be defined in each country, and within each country, in each geographical region.
2. The unmet need in antenatal services needs to be rectified urgently in order to minimize the number of new fistulas occurring.
3. The need for education and training has to be addressed for birth attendants, community nursing, and fistula surgeons.
4. Training centres for fistula surgeons need to be identified and new ones established, according to population matrix. Training should be systematic and structured using assessment tools such as those developed by FIGO with ISOFS.
5. Audit and research must be developed in order to ensure that quality and advances in treatment methods are ensured.
6. National strategies need to be developed to empower individual nations to take charge of the women's and children's services in their country.

VI. Management of New and Established Vesicovaginal Fistulas

Management of VVF depends on whether the fistula is diagnosed within two or three months of its occurrence or whether the woman presents late with an established fistula. There is evidence that early catheter care will result in the cure of a significant minority of VVFs. **Figure 1** describes the algorithm for the management of women who have both early fistulas, defined as those that have occurred within 75 days of presentation, and established fistulas, defined as those that are discovered more than 75 days after obstructed labour.

FIGURE 1

Algorithm to describe the management of fistula detected early (within 75 days of presentation) or later (more than 75 days after obstructed labour)



Classification of VVF

The Consultation believes that fistula audit research is considerably hampered by the plethora of VVF classification systems, of which we believe there are 32. The Consultation feels that the fistula system that is able to relate its classification to outcome is the classification that should be used in the next few years. The Waaldijk Classification is the only one that has been used to document sufficient numbers of patients from diagnosis to follow-up (Figure 2). Figure 2 shows the Waaldijk Classification which involves precise measurements of the distances between the external urinary meatus and the distal edge of the fistula, together with the widest diameter of the fistula. Fistulas are classified into types I, II and III. Type III fistulas are those fistulas other than vesicovaginal fistulas and include recto-vaginal fistulas and uretero-vaginal fistulas. The Waaldijk Classification of Types I and II is illustrated in Figure 3 and described below.

FIGURE 2
The Waaldijk Classification for Fistula

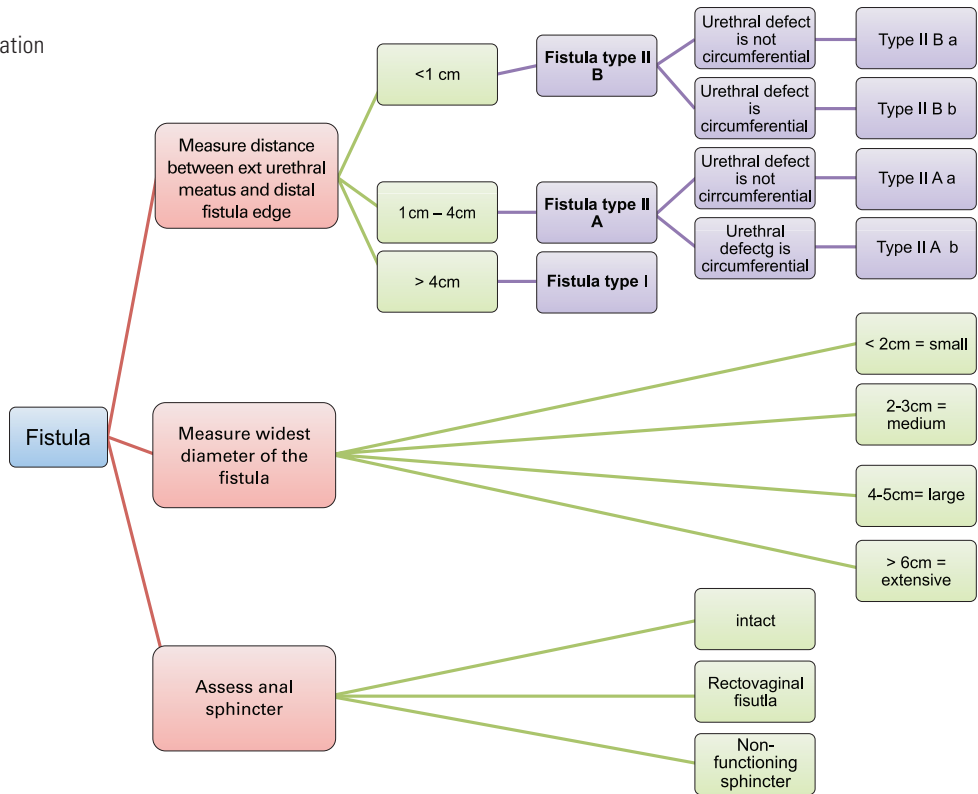
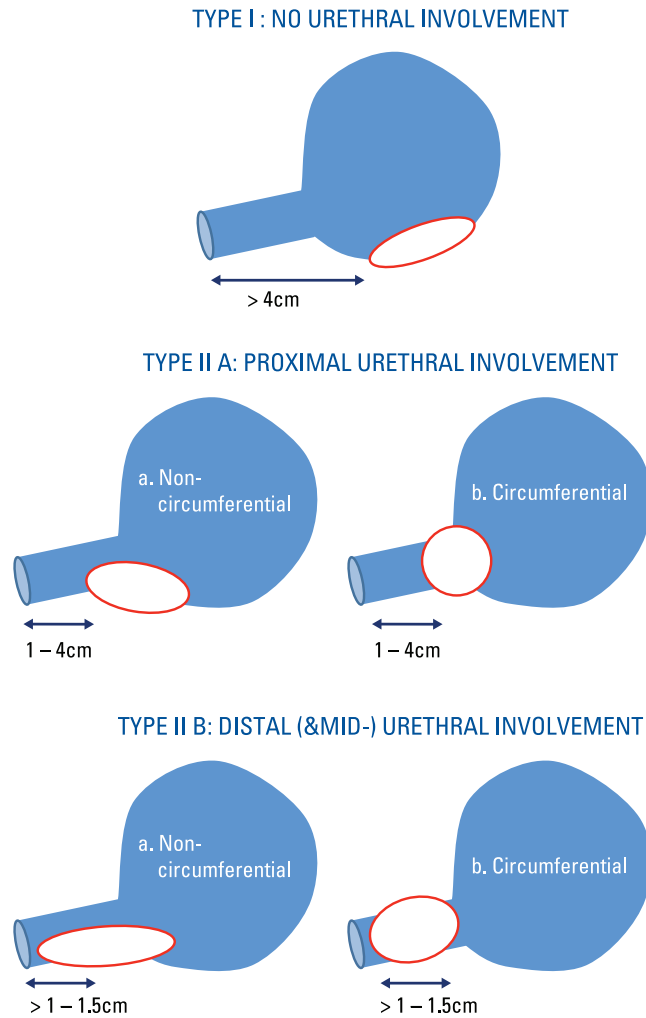


FIGURE 3
The Waaldijk Classification
for Fistula



If catheter drainage fails, then fistula repair will be necessary.

There are certain principles behind fistula repair:

- Necrotic tissue must be removed prior to fistula repair.
- Adequate postoperative care is essential.
- Fistula repair must only be undertaken by a properly trained surgeon.
- Proper follow up should be arranged.

Table 2 indicates the type of fistula closure that should be used depending on the type of fistula.

TABLE 2 Surgical Techniques for the Closure of Type I and Type II VVFs

| | Bladder / Urethra Direction of Closure | Pubocervical Fascia / Urethral Support | Anterior Vaginal Wall Closure |
|-----------|---|---|--|
| Type I | Any according to common sense | No special measures | Adaptation |
| Type IIAa | Transverse | Transverse repair (+ fixation) / sling | Transverse adaptation |
| Type IIAb | Circumferential end-to-end | Refixation / sling | Transverse adaptation |
| Type IIBa | Longitudinal (+ transverse) urethral tissue | Refixation / sling | Flap |
| Type IIBb | Longitudinal + circumferential non-urethral tissue | Refixation / sling | Flap |

Recommendations

1. The comprehensive use of an indwelling catheter with free urinary drainage should be instituted for all patients who have undergone either an emergency caesarean section, or a traumatic vaginal delivery after obstructed labour.
2. When fistula surgery is necessary, the woman must be assured of the surgeon's competence to carry out her procedure.
3. It is recommended that further research is needed into the classification of fistula, not only to further validate the Waaldijk Classification, but also if other classifications are proposed for development.
4. There is a need to compare different surgical approaches to fistula within the context of randomized controlled trials using the Waaldijk Classification to precisely describe the fistulas.
5. Long-term follow up of fistula patients is recommended in order to study the outcome of both conservative and surgical management and, in particular, to determine its effect on quality of life.
6. When reporting the outcome after fistula repair, authors should make a clear distinction between fistula closure rates and postoperative incontinence rates, specifying the time at which follow up was carried out.

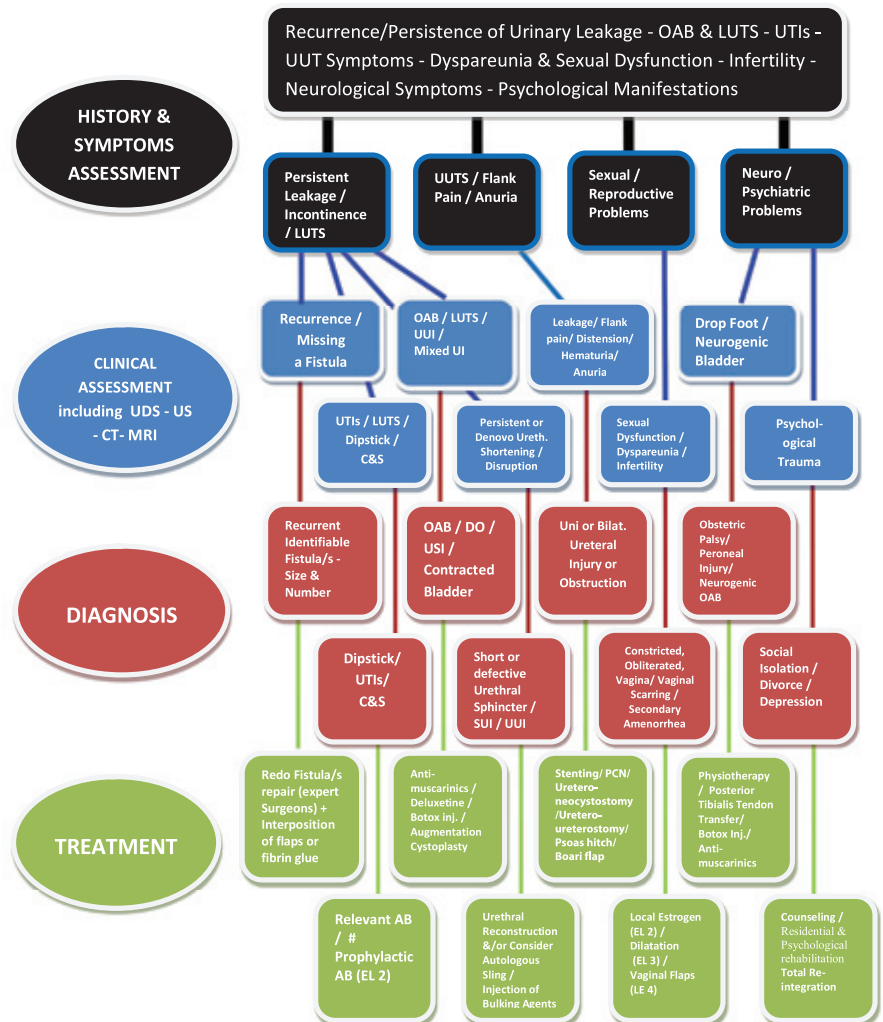
VII. Management of the Complications of Vesicovaginal Fistula

The complications of VVF are many but include:

- Persistence or recurrence of urinary incontinence
- Persistence of lower urinary tract symptoms or occurrence of new lower urinary tract symptoms, including overactive bladder
- Urinary tract infections
- Upper urinary tract symptoms, including loin pain
- Dyspareunia and sexual dysfunction
- Infertility
- Neurological symptoms
- Psychological problems and mental illness

Figure 4 shows the flow diagram for each of these classes of problem.

FIGURE 4
Management of Complicated
Vaginal Fistula



Recommendations

1. A care programme for failed repairs with persisting incontinence after a successful repair needs to be in place.
2. It is recommended that surgical treatment of postoperative stress incontinence should only be considered six months after fistula repair.
3. Autologous material should be used when a graft or sling is required and there is no place for synthetic sling material.
4. In order to prevent new fistulas in women who become pregnant after a fistula repair, waiting homes should be provided to ensure that each woman is able to have an elective caesarean section when she goes into labour.
5. In recurrent identifiable fistula take note of the size and number. This kind of fistula is better repaired by a well-experienced fistula surgeon. It is important to use tissue interposition like a Martius flap or fibrin glue.
6. With urinary tract infections or abscess formation, antibiotics must be given before and after the repair according to culture and sensitivities.
7. Patients complaining of persistent leakage due to urgency incontinence may try antimuscarinics, botulinum toxin injection or even augmentation cystoplasty in small, contracted or poorly compliant bladders.
8. Those with a shortened or disrupted urethra before or after repair must be treated with urethral reconstruction autologous slings or injection of bulking agents delivered trans- or peri-urethrally.
9. In cases with unilateral or bilateral ureteric ligation or injury, early diagnosis is life-saving. Patients must be promptly treated by endoscopic ureteral stenting percutaneous nephrostolithotomy (PCN) or ureteric reimplantation.
10. Patients complaining of contracted vagina and dyspareunia with sexual dysfunction may use local estrogen, vaginal dilatation or may require the surgical creation of vaginal flaps to augment the vagina.
11. Patients who develop dropped foot may respond to physiotherapy or require tibialis tendon transfer. Women with neurogenic overactive bladder (OAB) may benefit from detrusor muscle botulinum injections if antimuscarinic drugs fail.
12. Psychological trauma, social isolation and depression are best treated by counselling and psychological rehabilitation.

VIII. Social Reintegration of Treated Women

Social integration is defined as appropriate interventions that help women with obstetric fistula overcome physical, psychological and socio-economic challenges, freely identified by them, in order to enhance their return to the communities and social networks of their choosing, such that the risk of them presenting with another fistula is minimized.

The aim of social reintegration is to break the fistula recurrence/occurrence cycle in which the woman's physical state is inextricably connected to her mental state and her socio-economic situation.

Social reintegration should be seen as happening from the time the leaking of urine becomes manifest, and every subsequent intervention should have the reintegration of the woman, back into her community, as the primary goal. So, social reintegration is the responsibility of everyone who cares for the woman.

Social reintegration can be usefully looked at within a matrix, as shown in **Table 3** where the three elements of physical, psychological and socio-economic status are looked at in terms of the facility for treating the patient within her community and the political environment.

TABLE 3 Social Reintegration Matrix

| Element | Level | | |
|--|---|---|--|
| | Facility | Community | Political |
| Physical Improved physical health | Early detection Rehabilitation Skilled surgeon Timely repair Designated space | Outreach Health education Follow up | Allocate funds for treatment |
| Psychological Improved mental health | Psychosocial therapy (e.g. counselling) | Advocacy and sensitization Follow up | Raise awareness on issues of stigmatization |
| Socio-economic Increased social connection | Vocational skill training Linkage with existing programmes | Microcredit or finance Follow up | Link up with ongoing national poverty alleviation programmes |

Recommendations

1. Social reintegration is important for all women with obstetric fistula. It is the process by which women are helped to overcome physical, psychological and socioeconomic challenges, freely identified by them, in order to enhance their level of social functioning in communities and social networks of their choosing, so that the risk of them presenting with another fistula is minimized.
 2. Social reintegration should be used for all women. However, this series of interventions can be performed by any trained care worker, providing that it focuses on making the woman part of her social fabric again, and commences from the time leaking of urine becomes manifest.
 3. Social reintegration should be designed to break the fistula recurrence cycle in which the woman's physical state is inextricably connected to her mental state and her socio-economic situation.
 4. Early successful surgical repair or catheter management is highly recommended and is likely to be the only thing needed for social reintegration. Surgery should be performed as soon as possible by a skilled surgeon, and preferably within three months of developing the fistula, as this is likely to limit the length of time the woman is seen as abnormal by her family or community and thus perceived as an outcast.
 5. Social reintegration should start in a designated space where women can recuperate, perhaps within the repair facility or nearby, rather than going home and encountering the risk of behaviours which may make it likely that a recurrence of fistula occurs, due to an exacerbating physical event, such as early sexual intercourse or heavy work. Also, peer counselling is more likely to be available in this space.
 6. Surgeons and other care workers should consider social reintegration as not just a social tool but also as a means of ensuring that adequate follow up of the postsurgical improvement in quality of life is done and reported on. At the least, there should be a review of individually defined success of surgery and surgical outcomes, including continence and return to fertility and/or sexual life, as desired by the woman.
 7. Appropriate counselling messages about the risk factors and causes associated with fistula should be targeted at family members (including husbands) and the community. This can help to overcome the stigma, discrimination, and misconceptions surrounding the condition and enhance her community inclusion. It is then an opportunity to make changes so that the woman does not present with another fistula in the future.
 8. Counselling should be seen as an opportunity for health providers to understand the socio-economic, psychological, and physical experiences that are faced by girls and women living with fistula, before and after surgery, so that they may give meaningful help. This will also help to generate knowledge on social reintegration processes, and will help in the planning of a broader range of outcomes for women living with fistula.
 9. Social reintegration should include assistance with education and life skills, and encouragement of private initiatives through vocational-skills development and microcredit support. If this is freely chosen, it will not keep a woman away from her community unduly, and will help her regain or improve her previous economic status and enhance her self-sufficiency and community inclusion.
-

10. Social reintegration should include vocational-skills training, with the aim of providing women with alternative ways to generate income, without jeopardizing their recuperation, by teaching them a trade which is economically viable within their community.
 11. Institutional reintegration services should be incorporated into existing community activities or programmes directed to empower women (e.g. education, skills training, income generation, and self-esteem).
 12. Reintegration programmes should develop criteria to determine where support with socio-economic interventions should be given, as funds may be limited and fistula consequences can vary dramatically by country and region. They should also be careful not to increase the burden of stigma and therefore, inadvertently impede reintegration. Of particular concern should be those women who are still incontinent, those who are deemed incurable, those who have no children, and those who have lived with fistula for a long period of time.
 13. Social reintegration programs need to consider the potential ethical dilemmas in reintegration. These include providing targeted financial support or high-value goods to women with fistula in poor communities, other than as part of a community approach.
 14. Social reintegration should seek to involve women who have been successfully reintegrated into their communities. These women can be viewed as motivational mobilizers and can contribute to community mobilization movements for safe motherhood, fistula-case mapping, and referrals for treatment. Women should have a choice as to whether they wish to be involved in such advocacy activities.
 15. Social reintegration programmes should be monitored and evaluated in order to collect correlates of success and failure, and to help understand socio-cultural backgrounds, so that a context-specific approach can be used to design and deliver effective, feasible reintegration programmes.
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better life
relationships
fertile laugh mother isofs intercourse wife productive
supported confident economic empowerment new life cured
alive sexual life accepted strong
repaired dignity proud family joy
interaction self esteem training daughter socialise
children triumph continent smile
reintegration status marriage
job living empowered free sister healthy
participation skilled husband normal
happiness agents of change
education

Evidence-Based Medicine Overview of the Main Steps for Developing and Grading Guideline Recommendations

P. Abrams, S. Khoury, A. Grant

Introduction

The International Consultation on Urological Diseases (ICUD) is a non-governmental organization registered with the World Health Organisation (WHO). In the last ten years, consultations have been organized on BPH, prostate cancer, urinary stone disease, nosocomial infections, erectile dysfunction and urinary incontinence. These consultations have looked at published evidence and produced recommendations at four levels: highly recommended, recommended, optional and not recommended. This method has been useful but the ICUD believes that there should be more explicit statements of the levels of evidence that generate the subsequent grades of recommendations.

The Agency for Health Care Policy and Research (AHCPR) have used specified evidence levels to justify recommendations for the investigation and treatment of a variety of conditions. The Oxford Centre for Evidence-Based Medicine have produced a widely accepted adaptation of the work of AHCPR. (June 5th 2001, www.cebm.net).

The ICUD has examined the Oxford guidelines and discussed with the Oxford group their applicability to the consultations organized by ICUD. It is highly desirable that the recommendations made by the consultations follow an accepted grading system supported by explicit levels of evidence.

The ICUD proposes that future consultations should use a modified version of the Oxford system which can be directly “mapped” onto the Oxford system.

1. First Step

Define the specific questions or statements that the recommendations are supposed to address.

2. Second Step

Analyze and rate (level of evidence) the relevant papers published in the literature.

The analysis of the literature is an important step in preparing recommendations and their guarantee of quality.

2.1 What papers should be included in the analysis?

- Papers published, or accepted for publication in the peer-reviewed issues of journals.
- The committee should do its best to search for papers accepted for publication by the peer-reviewed journals in the relevant field but not yet published.
- Abstracts published in peer-reviewed journals should be identified. If of sufficient interest, the author(s) should be asked for full details of methodology and results. The relevant committee members can then “peer review” the data, and if the data confirms the details in the abstract, then that abstract may be included, with an explanatory footnote. This is a complex issue – it may actually increase publication bias as “uninteresting” abstracts commonly do not progress to full publication.
- Papers published in non-peer-reviewed supplements will not be included. An exhaustive list should be obtained through:
 - I. The major databases covering the last ten years (e.g. Medline, Embase, Cochrane Library, Biosis, Science Citation Index).
 - II. The table of contents of the major journals of urology and other relevant journals, for the last three months, to take into account the possible delay in the indexation of the published papers in the databases.

It is expected that the highly experienced and expert committee members provide additional assurance that no important study would be missed using this review process.

2.2 How are papers analyzed?

Papers published in peer-reviewed journals have differing quality and level of evidence. Each committee will rate the included papers according to levels of evidence (see below).

The level (strength) of evidence provided by an individual study depends on the ability of the study design to minimize the possibility of bias and to maximize attribution.

It is influenced by:

The type of study, whose hierarchy is outlined below:

- Systematic reviews and meta-analysis of randomized controlled trials
- Randomized controlled trials
- Non-randomized cohort studies
- Case-control studies
- Case series
- Expert opinion

How well the study was designed and carried out

Failure to give due attention to key aspects of study methodology increases the risk of bias or confounding factors, and thus reduces the study’s reliability.

The use of **standard checklists** is recommended to insure that all relevant aspects are considered and that a consistent approach is used in the methodological assessment of the evidence.

The objective of the checklist is to give a quality rating for individual studies.

How well the study was reported

The ICUD has adopted the CONSORT statement and its widely accepted checklist. The CONSORT statement and the checklist are available at www.consort-statement.org.

2.3 How are papers rated?

Papers are rated following a level of evidence scale.

ICUD has modified the Oxford Centre for Evidence-Based Medicine levels of evidence.

The levels of evidence scales vary between types of studies (i.e., therapy, diagnosis, differential diagnosis/symptom prevalence study) the Oxford Centre for Evidence-Based Medicine Website: www.cebm.net.

3. Third Step: Synthesis of the Evidence

After the selection of the papers and the rating of the level of evidence of each study, the next step is to compile a summary of the individual studies and the overall direction of the evidence in an **Evidence Table**.

4. Fourth Step: Considered Judgment (Integration of Individual Clinical Expertise)

Having completed a rigorous and objective synthesis of the evidence base, the committee must then make a judgment as to the grade of the recommendation on the basis of this evidence. This requires the exercise of judgment based on clinical experience as well as knowledge of the evidence and the methods used to generate it. Evidence-based medicine requires the integration of individual clinical expertise with the best available external clinical evidence from systematic research. Without the former, practice quickly becomes tyrannized by evidence, for even excellent external evidence may be inapplicable to, or inappropriate for, an individual patient. On the other hand, without current best evidence, practice quickly becomes out of date. Although it is not practical to lay our “rules” for exercising judgment, guideline development groups are asked to consider the evidence in terms of quantity, quality, and consistency, as well as applicability, generalizability and clinical impact.

5. Fifth Step: Final Grading

The grading of the recommendation is intended to strike an appropriate balance between incorporating the complexity of type and quality of the evidence, and maintaining clarity for guideline users.

The recommendations for grading follow the Oxford Centre for Evidence-Based Medicine. The levels of evidence shown below have again been modified in the light of previous consultations. There are now four levels of evidence instead of five.

The grades of recommendation have not been reduced and a “no recommendation possible” grade has been added.

6. Levels of Evidence and Grades of Recommendation for Therapeutic Interventions

All interventions should be judged by the body of evidence for their efficacy, tolerability, safety, clinical effectiveness and cost-effectiveness. It is accepted that, at present, little data exists on cost-effectiveness for most interventions.

6.1 Levels of evidence

Firstly, it should be stated that any level of evidence may be positive (the therapy works) or negative (the therapy doesn't work). A level of evidence is given to each individual study.

| Level of Evidence | Criteria |
|-------------------|--|
| I | <ul style="list-style-type: none"> ▪ Incorporates Oxford 1a, 1b ▪ Usually involves: <ul style="list-style-type: none"> ▪ meta-analysis of trials (randomized controlled trials [RCTs]) or, ▪ a good-quality RCT or, ▪ “all or none” studies in which treatment is not an option (e.g. in vesicovaginal fistula) |
| II | <ul style="list-style-type: none"> ▪ Incorporates Oxford 2a, 2b and 2c ▪ Includes: <ul style="list-style-type: none"> ▪ <i>low-quality RCT</i> (e.g. < 80% follow-up), ▪ <i>meta-analysis</i> (with homogeneity) of <i>good-quality prospective cohort studies</i> ▪ May include a single group when individuals who develop the condition are compared with others from within the original cohort group. ▪ There can be parallel cohorts, where those with the condition in the first group are compared with those in the second group |
| III | <ul style="list-style-type: none"> ▪ Incorporates Oxford 3a, 3b and 4 ▪ Includes: <ul style="list-style-type: none"> ▪ <i>good-quality retrospective case-control studies</i>, where a group of patients who have a condition are matched appropriately (e.g. for age, sex, etc.) with control individuals who do not have the condition ▪ <i>good-quality case series</i>, where a complete group of patients, all with the same condition, disease or therapeutic intervention, are described without a comparison control group |
| IV | <ul style="list-style-type: none"> ▪ Incorporates Oxford 4 ▪ Includes <i>expert opinion</i>, where the opinion is based not on evidence but on “first principles” (e.g. physiological or anatomical) or bench research. ▪ The <i>Delphi process</i> can be used to give expert opinion greater authority: <ul style="list-style-type: none"> ▪ involves a series of questions posed to a panel ▪ answers are collected into a series of “options” ▪ these “options” are serially ranked; if a 75% agreement is reached, then a Delphi consensus statement can be made |

6.2 Grades of recommendation

The ICUD will use the four grades from the Oxford system. As with levels of evidence, the grades of evidence may apply either positively (procedure is recommended) or negatively (procedure is not recommended). Where there is disparity of evidence, for example if there were three well-conducted RCTs indicating that Drug A was superior to placebo, but one RCT whose results show no difference, then there has to be an individual judgment as to the grade of recommendation given and the rationale explained.

Grade A recommendation usually depends on consistent level I evidence and often means that the recommendation is effectively mandatory and placed within a clinical-care pathway. However, there will be occasions where excellent evidence (level I) does not lead to a Grade A recommendation, for example, if the therapy is prohibitively expensive, dangerous or unethical. Grade A recommendation can follow from Level II evidence. However, a Grade A recommendation needs a greater body of evidence if based on anything except Level I evidence.

Grade B recommendation usually depends on consistent level 2/3 studies, or “majority evidence” from RCTs.

Grade C recommendation usually depends on level 4 studies or “majority evidence” from level 2/3 studies or Delphi processed expert opinion.

Grade D “No recommendation possible” would be used where the evidence is inadequate or conflicting and when expert opinion is delivered without a formal analytical process, such as by Delphi.

7. Levels of Evidence and Grades of Recommendation for Methods of Assessment and Investigation

From initial discussions with the Oxford group, it is clear that application of levels of evidence/grades of recommendation for diagnostic techniques is much more complex than for interventions. The ICUD recommends that, as a minimum, any test should be subjected to three questions:

1. Does the test have good technical performance?
For example, do three aliquots of the same urine sample give the same result when subjected to dipstick testing?
2. Does the test have good diagnostic performance, ideally against a “gold standard” measure?
3. Does the test have good therapeutic performance, that is, does the use of the test alter clinical management? Does the use of the test improve outcome?

For the third component (therapeutic performance) the same approach can be used as for section 6.

8. Levels of Evidence and Grades of Recommendation for Basic Science and Epidemiology Studies

The proposed ICUD system does not easily fit into these areas of science. Further research needs to be carried out in order to develop explicit levels of evidence that can lead to recommendations as to the soundness of data in these important aspects of medicine.

Conclusion

The ICUD believes that its consultations should follow the ICUD system of levels of evidence and grades of recommendation, where possible. This system can be mapped to the Oxford system.

There are aspects to the ICUD system that require further research and development, particularly diagnostic performance and cost-effectiveness, and also factors such as patient preference.

Summary of the International Consultation on Urological Disease Modified Oxford Centre for Evidence-Based Medicine Grading System for Guideline Recommendations

| Levels of Evidence | Description |
|--------------------|---|
| I | Meta-analysis of RCTs or high-quality RCT |
| II | Low-quality RCT or good-quality prospective cohort study |
| III | Good-quality retrospective case-control study or cohort study |
| IV | Expert opinion |

Abbreviation: RCT= randomized controlled trial

Summary of the International Consultation on Urological Disease Modified Oxford Centre for Evidence-Based Medicine Grading System for Guideline Recommendations

| Grades of Recommendation | Description |
|--------------------------|--|
| A | Usually consistent with level I evidence |
| B | Consistent level II or III evidence or “majority evidence” from RCTs |
| C | Level IV evidence or “majority evidence” from level II or III studies |
| D | No recommendation possible because of inadequate or conflicting evidence |

Abbreviation: RCT= randomized controlled trial

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EPIDEMIOLOGY OF OBSTETRIC FISTULA

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1.1 Introduction

Epidemiologic studies on obstetric fistula are few, are commonly institution-based rather than community based, retrospective rather than prospective, mostly including hospitalized women and reporting personal experience of surgeons. However, more relevant information is surfacing as the interest to address the problem is growing.

The geographic coverage of reports is uneven and partially reflects an uneven interest that might lead to skewed perception of prevalence, incidence and distribution.

For the present review, an exhaustive search of available literature was attempted in order to compile existing estimates of prevalence, incidence and geographical distribution of obstetric fistula, risk factors, impact, consequences, and health care seeking behaviour of these women. The search mainly used PubMed databases, Popline, Google Scholar and Google, and tracked references from the papers identified through these searches. Broad search terms used were: Incontinence, obstetric fistula, epidemiology, vesico-vaginal fistula (VVF), risk factors of obstetric fistula, determinants of obstetric fistula, impact of obstetric fistula, obstructed labour complications and access to fistula care. Searches were made by combining these key words and by using them separately to retrieve 290 articles: 138 being eligible.

Since studies with appropriate methodology for epidemiological estimates were few, and the present consultation on obstetric fistula is the first of its kind, we have extended the review to include a wider range of publications with relevant information. Community-based epidemiological studies, eligible hospital based case series and a few observational studies were given more detailed attention.

Apart from the quantitative research and review papers, some evidence-based qualitative research reports on impact and consequences of obstetric fistula were added. Articles that focused solely on the clinical aspects, and repair outcomes and techniques, were excluded.

Based on this search of available literature we here summarize estimates of prevalence, incidence and geographical distribution and the available evidence of risk factors, impact and consequences of obstetric fistula and the related health care-seeking behaviour.

Summary points

- This review includes a summary of data on the incidence, prevalence and distribution of obstetric fistula.
- Because of the scarcity of community-based studies the review is numerically dominated by institutionally based reports.
- Available literature on potential risk factors, impact, consequences and health care seeking behaviour of women with obstetric fistula has been included.

1.2 General Comments and Definitions

Obstetric fistula, an insignificant problem in developed countries, is still a major public health problem of low-income communities. Obstructed labour ends in death for many women in resource-poor communities. Those who survive often acquire obstetric fistula and live for years in physical pain and social disgrace.

These women are from a destitute social background and rarely access health institutions (1–2). As mentioned above, most studies on obstetric fistula are case series from health facilities. Although such patients who accessed health institutions and underwent clinical evaluation and treatment represent a valid proportion of the problem, the remainder, the group of women who could not access medical care, is the significant unknown. This leads to underestimation of the condition from hospital data. Very few community surveys were available, mostly based on non-validated self-reported symptoms, and some of these studies may have overestimated the magnitude of the problem.

Most commonly, obstetric fistula is an abnormal connection between the female genital tract and the bladder and rectum, but any portion of the lower urinary tract can be connected to any portion of the female genital tract. This review hence focuses on genital tract fistula due to:

- Prolonged obstructed labour
- Caesarean section
- Vaginal instrumentation in labour
- Symphysiotomy
- Ruptures/hematomas/infections
- Cervical cerclage/surgery in pregnancy and childbirth
- Other trauma during pregnancy and childbirth

The obstetric fistula is conventionally classified according to the anatomical structures involved (see Chapter 4).

1.2.1 Urinary tract

Injuries to the urinary tract are most common and as high as 99% of fistula cases were reported to have a urinary tract injury either in isolation, or in conjunction with bowel injury (3–4). Continuous urinary incontinence is associated with excoriation of perineal skin (ammoniacal dermatitis), infections, and stone formation in any available pocket either in vagina, bladder, urethra or ureter. Small fragments of stone (sandy stones) around the perineum sometimes indicate the existence of larger stone in the bladder or vagina.

- a. Vesico-vaginal fistula is a communication between the vaginal wall and urinary bladder and it is the commonest type of obstetric fistula in the urinary tract (4–9). The extent and severity of the bladder injury depends on the amount of bladder tissue lost and thereby reduced bladder capacity, the amount of scar tissue in the vagina, the region of the bladder missing (affected), and the concurrent injury to the rectum or anal sphincter (10).
- b. Urethro- and uretero-vaginal fistulas are defects connecting the vaginal canal with the urethra and ureter respectively (1).
- c. Vesico-uterine and vesico-cervical fistula connects the bladder to the uterine cavity and cervical canal respectively and urine passes through the cervical os and vagina.

1.2.2 Injuries to lower alimentary tract

- a. Rectovaginal fistula (RVF) is the most common defect affecting the lower intestinal tract. The fistula connects the vagina and rectum resulting in incontinence of feces and flatus through vagina.
- b. Perineal tear (injury to the external and internal anal sphincter) is a disruption that often coexists with an extended defect, or may be confined to the sphincters as a result of obstructed or precipitated labour.

Rectal injury alone is less common than combined urinary/intestinal tract injuries. In patients presenting with VVF, between 6% and 24% have the combination of a VVF and rectal injuries (3,11–13). A study by Naidu found RVF to exist concurrently with VVFs in only 15 out of 208 patients (7.2%) (12). Among 419 patients, Carpenter found 84.3% with isolated VVF, 11.3% had both RVF and VVF, 4.4% had a RVF alone, totalling over 15% of women with obstetric fistula also having RVF (5). Isolated rectal injuries are less common than combined rectal and bladder fistulas (3,5,14). In a series of 14,928 women operated at the Addis Ababa Fistula Hospital, 14,876 (99.7%) had uro-vaginal fistula and the rest, 52 women (0.3%), had an isolated RVF (3). Among the 14,876 with uro-vaginal fistula, 1,973 (13.2%) also had RVF. However, in a review of hospital records of 24 tertiary care facilities in India, isolated RVF occurred in 12.1% of the patients, and the combination of genitourinary and rectovaginal fistulas occurred in 1.2%. The most common type of fistula in that series was, similar to other reports, genitourinary with 86.6% (15). In contrast to the urogenital fistulas, the magnitude of anal sphincter involvement in obstetric fistula patients is less well documented (13).

Most literature on obstetric fistula treats it as one entity and rarely specifies the precise anatomy. The present review will focus on the epidemiology of obstetric fistula in general. Although terms, such as gynecological fistula, uro-genital fistula and genito-urinary fistula are used in the etiological studies of fistula from trauma, sexual violence, lower pelvic surgery, malignancy and radiation (16–18), the current review is limited to obstetric causes.

Summary points

- This review focuses on genital fistulas of obstetric origin
- The urinary tract or lower alimentary canal are often injured from obstetric trauma either alone or together
- The fistula is classified according to the anatomical structure involved, i.e. vesicovaginal, rectovaginal, urethrovaginal, ureteric fistula, vesicouterine fistula, etc.

1.3 Global Burden of Obstetric Fistula: Incidence, Prevalence and Distribution

1.3.1 Incidence of obstetric fistula

The incidence of obstetric fistula ideally should be determined by prospectively following women at risk (pregnant women) during labour and the postpartum period. However, most available studies on incidence were based on retrospective record reviews, which used hospital deliveries taband/or gynecologic admissions as the denominator for obstetric fistula incidence estimation during the study period (19–22).

The only prospective population-based study on obstetric fistula incidence is from West Africa (23–24). A total of 19,342 pregnant women were followed through pregnancy until 42 days postpartum in six main cities of the six West African countries and two small towns in Senegal. Data collection was based on women's self-report on interviews and followed by a gynecological examination for those who mentioned having symptoms. However, the authors did not publish the questions posed to obtain information on obstetric fistula (23). The overall incidence reported was 10.3 cases (95% CI: 0–37) of obstetric fistula per 100,000 deliveries. Since all the cases identified were from rural areas of Senegal, rural incidence of obstetric fistula was estimated to be 124/100,000 deliveries (95% CI: 15–446). On the basis of this study, the authors estimated about 33,451 new cases (95% CI: 4,050–120,413) as a minimum annual incidence of fistula in rural sub-Saharan Africa (24).

Other reports from health institutions with specific denominators such as total hospital deliveries and clearly defined (explained) cases with obstetric fistula produced estimates that varied from 0.6 (Niger) to 6.5 (Eastern Nigeria) admitted cases of women with obstetric fistula per 1,000 deliveries during the study period (19,21,25–27). However, the occurrence of fistulas and hospital deliveries (denominators) took place at different times.

Another recent report from Calabar in Nigeria used 37 women with obstetric fistula admitted during five years to estimate the incidence of 1 case per 122 parturients (i.e. 8.2/1,000 labouring mothers admitted) (28). The number of 4,510 deliveries during five years was too low and this might explain the high incidence compared to other reports. However, this variable estimate of incidence was highlighted by Wall *et al.* in 1998 as ranging from 1 to 10 per 1,000 deliveries (29).

A model-based estimate of obstetric fistula among women aged 15–44 years for developing countries in 1990, indicated an incidence of 8.68/100,000 (6). Although the underlying assumption is not clear, the authors estimated the global number of new obstetric fistula cases to be 82,000/year (6).

In a prospective study that focused on delivery-related and early postpartum complications (i.e. self-reported leakage of urine or feces one month following delivery), 557 women were interviewed (37% of the 1,506 participants in the study). They were residents of the slums of Dhaka, Bangladesh. The study identified no women with obstetric fistula, although three women reported to be incontinent postpartum (30). Clinical examination of these three women could not identify any fistula, which indicated that statistics based on self-reported symptoms are most likely to be overestimates. **Table 1** summarizes reports of occurrence of new of obstetric fistula cases per 1,000 deliveries.

TABLE 1 Summary of reports of the occurrence of new cases of obstetric fistula per 1,000 deliveries

| Author | Country | Design and Number (n) | Cases | Incidence/ 1,000 births |
|---|---|--|-------|--|
| Harrison 1985 (25) | Nigeria | Prospective follow up of 22,774 hospital deliveries | 79 | 3.5 |
| Ozumba <i>et al.</i> , 1991 (26) | Eastern Nigeria | Follow up of 11,299 hospital deliveries | | 6.5 |
| Danso <i>et al.</i> , 1996 (19) | Ghana, 1977–1992 | Retrospective record review of cases, per 157,449 hospital deliveries | 150 | 1.0 |
| Pruel <i>et al.</i> , 1998 (27) | Niger (Niamey) | Prospective follow up of 3625 hospital deliveries | 2 | 0.6 |
| Dolea <i>et al.</i> , 2000 (6) | Global, for developing countries (1990) | Model-based estimate, women of reproductive age (15–44), assumption not clear | | 0.8 (2.15% of neglected obstructed labour cases) |
| Vangeenderhuysen, <i>et al.</i> , 2001 (24) | 6 West African Countries | Multi-country, community based prospective longitudinal study, n=19,342 pregnant women | 2 | 0.10 (overall) 1.24 (rural) |
| Ijaiya 2004 (21) | Ilorin (Nigeria) | Review of 32,188 hospital deliveries and admission of cases | 34 | 1.1 |
| Fronczak <i>et al.</i> , 2005 (30) | Bangladesh | Interview, 30 days postpartum, n=557 | 0 | – |
| Orji <i>et al.</i> , 2007 (31) | Nigeria | Review of 14,682 hospital deliveries and admission of cases | 72 | 4.9 |
| Ali <i>et al.</i> , 2010 (32) | Sudan | Review of 4,585 hospital deliveries and admission of cases | 2 | 0.43 |

Other studies that used gynecological admissions or surgeries as the denominator, to estimate incidence of obstetric fistula, found estimates ranging from 14 to 23 cases per 1,000 admissions or surgeries (18,22). In another hospital study in Ethiopia, Gessesew *et al.* reported the incidence as high as 199/1,000 major gynecological surgeries (33). **Table 2** summarizes reports of new occurrence of obstetric fistula cases per gynecological surgeries or admissions.

TABLE 2 Summary of reports of new occurrence of obstetric fistula per gynecological admission or surgery

| Author | Country | Design and Number (n) | Cases | Reported Incidence |
|------------------------------------|---------------|-------------------------------------|-------|---|
| Kullima <i>et al.</i> , 2009 (22) | North Nigeria | Gynecological admissions | 80 | 14 /1,000 gynecological admissions 80/1,000 major gynecological surgeries |
| Sachdev <i>et al.</i> , 2009 (18) | Pakistan | 11,959 gynecological admissions | 278 | 23/1,000 gynecological admissions |
| Gessesew <i>et al.</i> , 2003 (33) | Ethiopia | 1,011 major gynecological surgeries | 201 | 199/1,000 major gynecological surgeries |

Studies determining the incidence of obstetric fistula with prospective follow up of pregnant women were very few; most available reports were retrospective analysis of obstetric fistula cases admitted per hospital deliveries during the study period. **Table 1** summarizes such study results used to estimate the range of obstetric fistula incidence (0.6 to 6.5 cases/1,000 deliveries) in this chapter.

1.3.2 Prevalence of obstetric fistula

1.3.2.1 Global estimates of prevalence

The most commonly referenced worldwide prevalence of obstetric fistula is two million cases, and 50,000 to 100,000 new cases per year (1,19,29,34–36) comes from an attempt made by Waaldijk and Armiya’u in 1993. Their aim was to provide an estimate of the global burden based on the number of women with obstetric fistula seen at their hospital and they published as a special contribution to the *International Urogynecology Journal* (37). This estimate, however, was suggested as a global number as well as an estimate for Africa (34), or for Africa and Asia (7), and was later referred to as “World Health Organization estimates” (35–36).

The more recent global prevalence estimate of over three million women with obstetric fistula was based on incidence estimates of obstructed labour, assuming that at least 2% of neglected obstructed labour cases would end up with fistula formation and assuming a low capacity for obstetric fistula repair (9). The estimates and assumptions, however, lack support from hard data or clarity of the epidemiological methods used.

In the model-based estimate, the global prevalence of cases of obstetric fistula was estimated to be 654,000 (with 262,000 in sub-Saharan Africa and 194,000 in India) for the year 1990 (6,38).

In a short survey by the World Health Organisation (WHO), carried out in 1991, countries from where fistula had been reported were noted. Many countries in Africa and South Asia were listed, but not all, and less from Latin America and the Middle East (**Figure 1**).

1.3.2.2 National estimates

There are varying estimates of prevalence of obstetric fistula based on self-reported fistula symptoms in Demographic Health Surveys (DHS) from different countries, and specific prevalence estimates adhering to survey methodology, but with different levels of strengths and transparencies. Reports from DHS attempt to provide representative national estimates. The proportion of respondents who reported to have ever experienced the symptom (incontinence) was used to estimate most of these national levels of prevalence of obstetric fistula, and the estimates range from 1% of ever-married women in Ethiopia to 2% of all women interviewed in Malawi (39).

The weighted average, calculated from these DHS results of incontinence, was highest in Malawi (4.7%) followed by Ethiopia (3.41%), Rwanda (3.3%) and Uganda (2.64%) (16). Based on these statistics, the lifetime prevalence of reported incontinence per 1,000 deliveries were estimated to range from 5.92 in Uganda to 16.4 in Malawi (16).

However, there is a general concern that these estimates from DHS might be far from the true estimate:

- Women's self-reports of maternal morbidities are known to be problematic (40)
- Symptoms reported as fistula – essentially, incontinence of urine and/or feces – may actually be those of another condition with similar symptoms and consequences (41)
- Data were collected using knowledge-based contingency questions and these are frequently biased towards the responses of those who lived in urban areas or are more educated (42–44). For example:
 - Only 23% of all Ethiopian women had ever heard of obstetric fistula, but 50% of women living in urban areas had heard the term compared with only 17% of those women living in rural areas
 - About 90% of women who had higher than secondary education had heard of obstetric fistula, but only 16% of uneducated women had heard the term
 - About 41% of the wealthiest women knew the term, compared with only 15% of the poorest women.
 - Thus, the women who were selected by the knowledge-based contingency question, to answer the specific questions on their own experience of fistula symptoms, were more likely to live in urban areas, are comparatively wealthy and better educated than the average for the entire population (43).

- Restriction of respondents to those with live birth will exclude all women whose first and only pregnancies ended with both stillbirth and fistula. This may result in an inaccurate estimation of the national prevalence of fistula. This inaccuracy may be due to:
 - Methodological omission of potential cases,
 - An incomplete understanding of the etiology of the morbidity due to biased sample selection, and
 - Distortions in the statistical associations between the experience of fistula symptoms and covariates of interest.
- It is possible that women with fistula are underrepresented in the housed population since women with fistula are cast out of their homes and no longer considered members of any household (43).

In a model-based estimate (6,38), the prevalence of obstetric fistula was estimated to be 51.35/100,000 for women of 15–44 years of age, and the prevalence in sub-Saharan Africa, India, and other Asian countries were estimated correspondingly to be 184, 76, and 36 per 100,000 (38).

A recent study conducted to estimate the prevalence of obstetric fistula in Malawi was a combined facility and community-based survey (45). Women aged 12 years and over were interviewed in the community; hospital records were reviewed and a total of 659 eligible cases included in the estimate (548 from the community survey and 111 from the hospital records review). Both community and facility based results were from nine randomly selected districts. Records of patients admitted to facilities within these nine districts were included in the analysis and selected women from these communities were interviewed as to whether they had continuous leakage of urine or not. The total number of women aged 12 years and over from these communities (from national figures) was used to calculate the prevalence. From such collected information prevalence of obstetric fistula was estimated to be 1.6/1,000 women aged 12 years and over.

The community surveys conducted in Bangladesh involved a multi-stage random sampling technique finally selecting the smallest administrative unit (the unions) where the data was collected by interviewing all ever-married women. However, the method was not sufficiently described. It was indicated that among 31,889 ever-married women, 54 women with incontinence were found to have fistula (again, there was no clear description as to how this was validated). The prevalence estimate reported was 1.69/1,000 ever-married women (46).

A total of 27,090 women aged 15 years and over in 19,513 households in 189 rural villages with 97,765 inhabitants, were used to determine the prevalence of obstetric fistula in seven rural regional administrative states of Ethiopia (47). It was a community survey used a multi-stage random sampling technique to select sufficient numbers for the interview. Clinical examination was done in those with a history of incontinence and the adjusted prevalence estimate of obstetric fistula per 1,000 rural women aged 15 years and over was 0.21 (95% CI 0.12–0.35).

A national prevalence of obstetric fistula per 1,000 rural women of reproductive age (using the national and regional number of 2005) was 0.22 (95% CI 0.14–0.36) based on standardized rates. For untreated women, the prevalence was 1.5/1,000, which corresponds to 26,819 women living with this problem in rural Ethiopia during the year 2005, and on average they would have had the fistula for eight years without resorting to any surgical treatment (47).

The few existing prevalence estimates based on studies at the community level and based on advocated survey methodology show consistency, with levels ranging from 1.5/1,000 women aged 15–49 years in Ethiopia to 1.69/1,000 ever-married women in Bangladesh (41,45,47). **Table 3** provides a summary of the published prevalence data from community surveys.

TABLE 3 Summary of prevalence estimates from community surveys in Asia, West Africa and East Africa

| Author | Methods | Sample Population (n) | Cases Identified | Prevalence |
|---|--|------------------------------------|------------------|------------------------------------|
| Kalilani-Phii <i>et al.</i> , 2010 (45) | Community survey & Facility data review <ul style="list-style-type: none"> ▪ Random selection ▪ Self-reported symptom | 3,279 women 12 years and above | 532+111 | 1.6/1,000 women 12 years and above |
| Walz <i>et al.</i> , 2003 (46) | Community survey <ul style="list-style-type: none"> ▪ Random selection ▪ Interview | 31,889 ever-married women | 54 | 1.69/1,000 ever-married women |
| Muleta <i>et al.</i> , 2007 (47) | Community survey <ul style="list-style-type: none"> ▪ Random selection (multistage) ▪ Interview Validated, by clinical examination | 27,070 women 15 years and above | 55 | 1.5/1,000 women 15 years and above |

1.3.3 Geographical and ethnic distribution

In a historic perspective, cephalopelvic disproportion is a product of human evolution, i.e. bipedalism and encephalization (48–49) that led to the increased risk of obstructed labour known to all societies. In countries with good access to obstetric emergency services, the condition is relieved in time to prevent the complications of long-standing incarceration, e.g. obstetric fistula. However, it may be an oversimplification to state that obstetric fistula is a problem of low-income countries. Obstetric fistula may occasionally occur in high-income countries with the most favourable maternal and perinatal mortality rates (50), but systematic reporting is rare.

More detailed statistical information from all countries of the world would give a more accurate picture of global distribution.

Although prolonged obstructed labour is by far the most important cause of obstetric fistula in low-income countries, it is not the only direct cause. Instrumental interventions and surgical procedures during pregnancy and labour are other causes, which may be more prominent in high-income countries. In a series of gynaecological fistulas treated at a specialised centre in Norway, 20% of the fistulas had occurred in connection with pregnancy and childbirth. In contrast to the typical pattern of sub-Saharan countries with VVF being the dominating injury with RVF as an additional complication in 13% (3), the Norwegian patients had almost exclusively rectal fistulas. The two cases of urinary tract injury were due to a uterine rupture and a misplaced cervical cerclage. These cases were collected over a period of 10 years and may represent underreporting but still represent extremely rare incidences in a country with roughly 60,000 deliveries per year. In a similar period, a centre in Denmark noted four vesicouterine fistulas after caesarean section (51). The rarity of such lesions may lead to underreporting and scarcity in publications. However, such cases indicate that obstetric fistula exists in all countries but with widely varying incidences and with different causative backgrounds.

Sub-Saharan countries, with the Indian subcontinent and Southeast Asia, undoubtedly represent the bulk of cases (**Figure 1**). However, the map shows the countries that reported obstetric fistulas only. Angola, Botswana, Central African Republic, Congo, Yemen, and Afghanistan are some of the countries where fistula probably exists at a considerable but unreported level at the time when the map was drawn (52). Within any country, it is the accessibility of emergency obstetric care services that is the decisive factor, which is probably a major reason why rural areas are hit so severely, compared with cities (24).

Figure 2 is complementary to that of **figure 1** and shows the 47 countries (yellow) with ongoing activity on end-fistula campaign (53). None of the maps however, are complete representations of the obstetric fistula distribution in the world.

The question as to whether there are ethnic differences predisposing for obstetric fistula, is difficult to answer. The ethnic and genetic variation in Africa alone is exceedingly high compared to the rest of the world. Ethiopia, from where the largest set of data is published (14,928 cases), had a high number of patients from the ethnic group (Amhara) with the shortest stature, and the fistula patients were significantly shorter than their background population, even when controlled for age (3). However, the study was not designed to address ethnic differences. Whether stunting is due to high altitude, iodine deficiency or other nutritional causes, or ethnic background, is hard to distinguish, particularly since ethnic background also is linked to socio-economic determinants and geography.

Figure 3 shows how the degree of stunting, assisted birth and access to road, vary in populations believed to have a high incidence of obstetric fistula (52).

Ethnic groups vary also in traditions of marriage, dietary habits and physical activity — factors that may be difficult to discriminate from purely ethnic, or rather genetic predisposition. With the modern knowledge of the substantial plasticity of individual development, exhibited during fetal and postnatal life, adapting to environmental conditions, it is plausible that such mechanisms are more important than belonging to a specific genetic group.

FIGURE 1

Countries where obstetric fistula has been reported according to the World Health Organization: Obstetric fistula – A review of available information (WHO/MCH/MSM/91.5) (53).

Note that white areas signify "not reported" rather than "not existing".

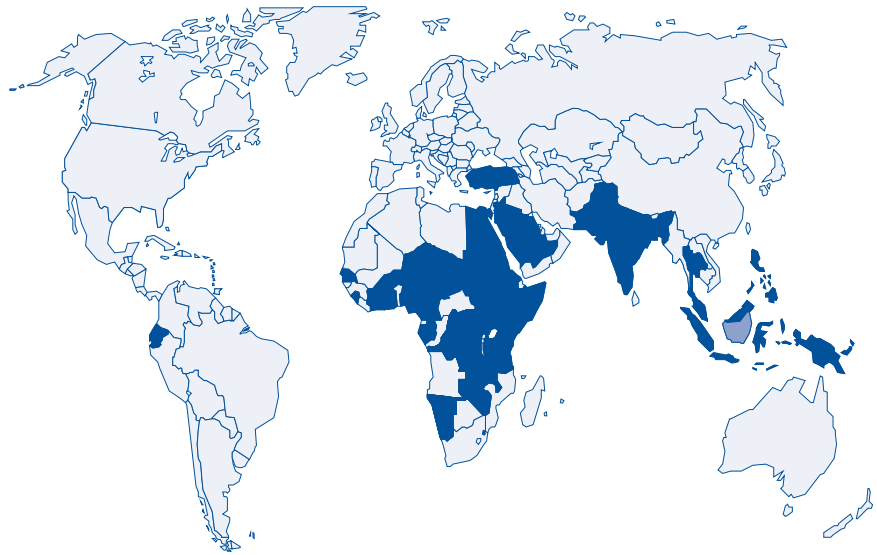


FIGURE 2

End-Fistula-Campaign was initiated by UNFPA and launched in 2003. The map is complementary to that of Figure 1 and shows the 47 countries (yellow) with ongoing activity.

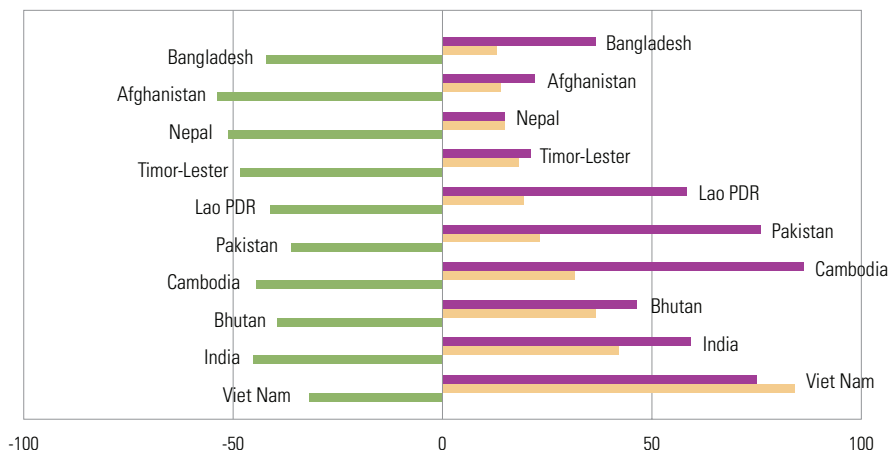
Source: Thematic Evaluation of National Programmes and UNFPA experience in the Campaign to End Fistula, Assessment of global/regional activities in Support of national programmes. Global Regional Report 2010;1:2(53).



FIGURE 3

The relationship of RAI (Rural Access Index) expressing the accessibility of road to rural dwellers, assisted births and risk of stunting in countries expected to have high incidence of obstetric fistula. The three factors are determinants for obstetric fistula. According to Kunieda M: Finding fistula patients in Asia.

Transport and Communications Bulletin for Asia and the Pacific 2007;76 (54).



Summary points

The results of this review of the magnitude of obstetric fistula suggest that:

- There is no reliable data for estimating global prevalence of obstetric fistula. The current global estimates of obstetric fistula vary from 654,000 to 3.5 million.
- Hospital based incidence estimates vary considerably from 0.6 to 6.5 per 1,000 delivery at the facility. These rates are underestimates since the studies include only those who accessed health services.
- There is only one empirical assessment of incidence of obstetric fistula, 1.24 per 1,000 deliveries (33,451 annual new cases), for rural sub-Saharan Africa.
- The model-based estimate for sub-Saharan Africa is 0.18 per 1,000 women of reproductive age however, details of the underlying evidence for this estimate is not publicly available.
- Statistics based on self-reported symptoms overestimate prevalence due to variations in case definition and inadequate case ascertainment and clinical verification.
- National estimates of prevalence of non-treated obstetric fistula cases (following different survey methods) are consistent across countries in East Africa, West Africa and Asia, and range from 1.5 to 1.7 per 1,000 women interviewed.
- Underreporting due to stigma might result in underestimation of the magnitude of the problem.
- The geographic coverage of reports is uneven, which leads to skewed perception of prevalence, incidence and distribution around the world.

1.4 Causes of and Potential Risk Factors for Obstetric Fistula

1.4.1 Causes of obstetric fistula

Although the scope of this review demands focus at causes of obstetric fistula, the causes of non-obstetric fistula are critical to consider on a number of levels, in order to grasp the basic underlying disparities between wealthy and poorer nations.

One of the most tragic issues in the aspects of fistula is that the causes of this horrific disease are completely preventable. The causes of fistula stand as motivators for social change and, rightfully, as cause for international shame as we confront this huge burden of avoidable suffering. In order to design effective and efficient programs of fistula prevention, a sound understanding of the origin of fistula is a critical first step. No preventive intervention is possible without thoroughly understanding what we are trying to prevent. The disparity in the causes of fistula between wealthy and poor nations is a potential barrier to organized and harmonized international effort. Fistula in the developing world is a completely different issue from fistula in the wealthy world, and the differences boil down to cause.

In wealthy nations, fistula occurs primarily as a complication of medical and surgical therapy, and abdominal hysterectomy represents the single most common cause of fistula (54–55). Other procedures potentially complicated by fistula include surgery for genital prolapse, colorectal surgery, and caesarean section (56–58). Newer procedures for the treatment of stress urinary incontinence, particularly those involving the implantation of artificial mesh material, are a growing cause of fistula in wealthy countries (59).

A smaller subset of patients develop fistulas after radiation therapy, especially those done for gynecologic cancers (60). Even non-invasive measures such as the use of a pessary for prolapse or incontinence, has been associated with fistula (61). Gynecologic cancers can either present as fistula from erosion of tumour into the bladder, or as fistula resulting from a recurrence after failed therapy of some sort (51). And so, in the vast majority of cases in the West, fistula is essentially an iatrogenic phenomenon.

Just as pelvic surgery dominates as the most common cause of fistula in wealthy countries, iatrogenic fistulas occur in the developing world as well. Our evidence base in this area is just being developed, but it would seem that the relative incidence of fistula as a complication of caesarean section is much higher in the developing world than in first-world countries (62–63). This might be expected, as surgeons and medical officers across Africa and west Asia are often called upon to perform caesarean section in the direst clinical situations and in the most resource-poor environments. It is also impossible to discern with fistula after caesarean, which injuries are iatrogenic, that is, related to the performance of the caesarean, and which were simply the result of obstructed labour with the

caesarean done after the ischemic damage was already done. Hysterectomy is not uncommon as a cause of fistula, but in the developing world this would include significant numbers of caesarean hysterectomies, once again performed under the worst of circumstances.

There is a special class of “iatrogenic” fistula in the developing world, if one is to take the widest possible interpretation of the term. Here we refer to fistula related to harmful traditional practices. The term “female genital cutting” (FGC) refers to an extremely broad range of practices. These interventions may be performed by trained medical personnel in traditional institutional settings, but in the vast majority of settings they are done in the community by untrained personnel. And fistula can result, although this seems to happen relatively uncommonly, if we limit our discussion to female genital cutting forms such as clitoridectomy and infibulations (64). Other forms of female genital cutting are practiced under the Hausa term “gishiri cut” (65). A full discussion of the range of practices and their place in local cultures would range far beyond the mandate of this chapter. In general, gishiri refers to a practice where a practitioner of traditional medicine inserts a large knife into the vagina or urethra. The large cuts can often be a direct cause of fistula. These procedures seem to be done for a variety of indications, from irregular menses, dyspareunia, infertility, and a number of other vague complaints. Another potentially harmful traditional practice comes under another Hausa name “wankan jego” or “wankan biki” (29). Especially after the delivery of a child, women often receive douches with special cleansing solutions. The solutions used are often quite alkaline, and can cause fistula directly through chemical injury.

Giving a woman water to drink, to aid expulsion of the baby when the bladder is full during delivery may increase the risk of fistula, and family members resisting necessary medical examination by male clinical staff, are some other harmful traditions with potential association with fistula formation (66).

Tragically, we live in an age when another cause of fistula is sexual violence against women, “traumatic fistula”. To date, this type of fistula is very inhomogeneous in distribution, being far more common in conflict areas. As systematic, large-scale rape is applied to wide swaths of the female population as a tool of terror, more traumatic fistulas are being seen (67). The term “traumatic fistula” might also be applied in place of “post-coital fistula”, in areas where the practice of early marriage is prevalent, when girls who have barely reached menarche are subjected to full sexual activity as married women (5,68). In some studies, coital injury was the main etiological factor for rectovaginal fistula or third-degree perineal tear occurring alone (5,68).

Pelvic trauma from more mundane accidents and injuries can occur anywhere, whether in the West or the developing world, but we have no real data on the magnitude of this problem. Taken overall, this is not a major cause of fistula problem.

Just as they do in the West, gynecologic cancers in the developing world can cause fistula. Since resources for multidisciplinary therapy for gynecologic cancer are so limited in the poorest parts of the world, these tumours often present at an advanced stage, and erosion of aggressive cancers can cause fistula. Since repair is not generally attempted in this setting, these patients are unlikely to be captured when reporting large series of fistula experience, which tend to focus on findings at surgery. So, we have no objective information on the scale of this subset of fistula disease.

The same could be said for fistulas caused by infection. Especially in the context of Acquired Immune Deficiency Syndrome (AIDS), gynecologic infections can be so severe and aggressive that massive tissue loss occurs and fistula ensues. But, since these women are not treated surgically, we have no meaningful data in the literature to address the scale of this cause of fistula.

Fistula of obstetric origin is a common problem of low-resource settings and documented in over 90% of women with genital fistula (1,3,7,69–76). The most common cause of obstetric fistula is prolonged, obstructed labour (1,8,66,69,76–80). Cephalopelvic disproportion is reported as the major cause of obstructed labour and both maternal and fetal factors play a role (81). The reports from teaching hospitals in Nigeria that the cause of vesicovaginal fistula was 95% in 1981 and 60% in 2005 may indicate a trend of decline (74).

However, this information from a referral and teaching hospital, which is inaccessible to rural women with fistula, has been acknowledged to be non-representative, as this public health problem is still very common in some parts of northern Nigeria (74). Even in conflict areas where traumatic fistula is a problem, obstetric fistula, as a complication of untreated obstructed labour, remains the major cause of fistula today (82).

Although there is very little documented evidence about the labours that cause the pelvic damage and corresponding fistula, the fact that the labours had lasted for days, with the likely ischemic damage of the vagina and surrounding structures, strongly supports the concept that neglected obstructed labour is the cause of fistula formation. The strong association reported could be a stronger support for a causative link (83) and the available explanation is that, during the long ensuing labour, the presenting fetal part presses relentlessly on the pelvic tissues, often pinned between the fetal head and the bones of the pelvis, and that wide-field ischemia results, large areas of tissue are lost, and fibrosis occurs as the injury heals (76,84).

Obstetric fistula as described by Arrowsmith *et al.* in 1996, is different from postsurgical vesico-vaginal fistula, which is usually the result of focal trauma to otherwise healthy tissues. The obstetric fistula is the result of a “field injury” to a broad area which may result in total urethral loss, stress incontinence, hydro-ureteronephrosis, renal failure, recto-vaginal fistula formation, rectal atresia, anal sphincter incompetence, cervical destruction, amenorrhea, pelvic inflammatory disease, secondary infertility, vaginal stenosis, osteitis pubis, and foot-drop (84).

Where obstructed labour was the cause of the fistula, the mean length of labour was reported to range from 38 hours (18) to 4 days (79). The labour was shortest in those women who developed RVF alone and was longest in women who subsequently developed both RVF and VVF (5). Poor monitoring of labour, including the pattern of urination during labour, was said to be the reason for obstetric fistula formation (85). About 64% of these women in Tanzania and 58% in Uganda said they could not pass urine during labour, passed only small amounts, could only urinate at the beginning of labour, or urinated only once during labour (85).

Iatrogenic fistula (fistulas arising as a result of obstetric interventions and surgical complications) in Africa, are important in terms of the need for expanded resources, better training, and in external supervision of outcomes. This was documented in 1996 in a study by Danso *et al.*, which reported that 36 (22%) of 164 fistulas were due to complications of surgery (19).

But, obstetric fistula as a complication of obstructed labour so dominates the spectrum of etiology that most discussions of fistula are by default referring to this particular cause. However, the frequency of women's perceptions that their fistula was caused either by the doctor accidentally piercing the bladder or by the procedure/instruments used during delivery is also high (85). Studies however, were unable to independently confirm women's reports of surgical error leading to fistula, in the presence of prolonged obstructed labour, which might have already caused the damage before interventional procedures were used. Women's perception about the cause of fistula however, is also dependent on the educational status of women (86).

The basic underlying disparity in the causes of fistula between wealthy and poorer nations has led to a divide of sorts between surgeons of these two different communities. To a surgeon in Ireland or the United States of America, the term fistula conjures up a mental picture of a focal injury occurring as a result of a mishap during pelvic surgery. The western literature on fistula often focuses on diagnostic maneuvers to confirm the presence of a tiny fistula and locate it, on conservative therapies, and application of minimally invasive techniques. For a surgeon in Mali or Rwanda, fistula means something altogether different, as they cope with potentially huge expanses of tissue loss, a wide range of associated injuries (84) emanating from the obstructed labour, the potential destruction of any mechanism of continence, and the need for large, sometimes heroic interventions. Clearly these two faces of fistula represent opposite poles along a spectrum of injury.

It has only been recently that the issue of obstetric fistula has grown in its international exposure such that our colleagues in wealthy nations even understand what African surgeons are talking about. So, this basic difference in the cause of fistula in these two contexts is something that must be recognized and addressed. African surgeons can benefit greatly from new procedures developed by western medicine and from the breadth of teaching and training resources available to address the broad range of plastic surgical, urologic, gynecologic and colorectal interventional skills that a fistula surgeon must possess, in order to help all comers with fistula. But, Western surgeons must recognize that African surgeons possess the bulk of the real-world experience in dealing with these horrific injuries.

More than in perhaps any other clinical settings, Western and African surgeons meet each other as equals. Western surgeons traditionally enjoy coming as teachers, and have been of great benefit to those from countries where the resources for training are huge compared to those in poorer nations. But Western surgeons interested in obstetric fistula must first come to grips with the reality that they must come first as students, to a clinical situation that is not like anything they might see in a Western practice. These challenges are based in the different causes of fistula.

1.4.2 Potential risk factors

Obstetric fistula is described to occur as the result of a cascade of obstetrical catastrophes that are summarized as the “Obstetric Fistula Pathway” (9). A study from Tanzania indicated that women from richer households consume more services than the poorest women, and that poorer, lesser-educated, and rural households use the least available health care (87). Kelly described obstetric fistula as a result of two obstructions, obstructed labour and obstructed transport (88). These obstructions coupled with lack of medical attention are common, and some address this failure of the state to provide prenatal preventive care and timely fistula repair as violations of human rights (35).

Scientific evidence with hard data are limited when thinking of the balance of social/demographic risks and benefit factors for obstetric fistula, however, reports from case series and personal experiences emphasize that early age at marriage, young age at first pregnancy, stature of women, parity, low status of women, the place of delivery, poverty, illiteracy, sex inequality, malnutrition, social and cultural issues, to family planning and the lack of emergency obstetric care are contributing factors associated with obstetric fistula (1–3,8,13,73,89–94).

1.4.2.1 Poverty as fundamental problem

It is commonly observed that poverty is the underlying problem in developing countries for obstructed labour and resulting fistula, as poor countries struggle to provide the very basic emergency obstetric services necessary to avoid maternal death and injury (4,35,95). Wealthy nations had the resources to make obstetric fistula disappear, while women in Africa and Southwest Asia face the same dangers in labour that women have endured for thousands of years (95). A critical analysis of secondary data from Tanzania and Uganda showed that reproductive health outcomes were worse for people living in poverty than for those from higher-income groups (87) with especially large gaps between women from the highest and lowest educational levels.

1.4.2.2 Poor nutrition

The nutritional state of the woman is also regarded as a determinant. Improved nutritional and environmental factors for young girls results in accelerated growth before puberty; however, in deprived girls, catch-up growth is often associated with delayed puberty and an extended period of growth (96). Nutritional improvement in pregnant women, whose pelvic skeletal growth had been restricted during childhood and early adolescence, is reported to lead to larger neonates and higher incidence of cephalopelvic disproportion (96). It was acknowledged by several researchers that malnutrition is not only the cause but also a consequence of obstetric fistula (76,97–98), however, there is no hard evidence based on observational research.

1.4.2.3 Age and parity as potential risk factors

Obstructed labour has been linked to the woman’s age and parity, the young primigravida being more likely to experience both obstructed labour and subsequent morbidity (14,96). The percentage of primiparas with fistulas varied from 27% in the study of 49 cases by Gharoro and Abedi to 81% in the study of 31 cases by Ibrahim *et al.* (1,19,21,33,71–73,75–76,78–79,93,99–101). There are no clear descriptions of uterine activity during obstructed labours, however, it was hypothesized that in

primigravida women, during mechanical obstruction in labour, the uterine contractions gradually weaken and then stop, however, in multiparous women, contractions continue until delivery or until uterine rupture occurs (102).

The association of primiparity with longer duration of labour (Odds Ratio 3.2 [2.3–4.5]) and stillbirth (Odds Ratio 1.9 [1.3–2.8]) was also documented (3) and controlling for age at delivery did not reduce the strength of these associations in the study.

Analysis of risk factors using logistic regression on deliveries in Niger, Nigeria, and Tanzania examined correlations with obstructed labour. The authors predicted how delaying childbearing could affect the occurrence of obstetric fistula. Using local data for prolonged labour and stillbirth rates, and assumptions on fistula formation rates, the authors predicted that “the proportion of women experiencing prolonged/obstructed labour would be reduced by 11.2% in Niger, 11.4% in Nigeria, and 13.1% in Tanzania if the risks associated with young maternal age at first delivery and primiparity were eliminated” (103).

A case control study in Nigeria with 241 cases and 148 controls found fistula patients to be younger in age and shorter in height than control patients (89). For Carpenter and colleagues who analyzed mean age of fistula occurrence, women with both RVF and VVF had the injury at a younger age compared to those with a VVF alone (5). In most of these studies, the reported age is often the age at the time of fistula repair (1,8,13–14,76,79).

On the contrary, other reports documented later age for the development of obstetric fistula. The peak age for acquiring obstetric fistula was 20 to 24 years among women seen at Addis Ababa Fistula Hospital (5), with an average age reported being about 20 years (3,5), those with RVF alone acquired their fistula at a younger age, mean 17.4 years (5).

Report from Nigeria indicated that only 23.8% women with fistula had their injury as teenagers, showing a shift of preponderance from teenagers to older women who would have already attained their optimum pelvic size (104). The authors thought that other factors, such as socio-cultural practices and religion, which limit the woman’s access to appropriate health care, may therefore be more important in developing VVF. Other studies also support that age at first marriage and age at fistula development was older than other women, which may indicate that poor access to Emergency Obstetric Care (EmOC) contributes more to this problem (1,19,31,77,101).

According to a report from Ghana, 31% of the cases got their fistula at 20–24 years of age, 21.3% when below 20 years of age, and 15.3% occurred in women between 40 and 45 years old (19). Orji and colleagues from Nigeria found that peak age for the occurrence of fistula was at 20–24 years (36.1%), with a mean of 24.8 years during 1994–2003 (31). Hilton and Ward highlighted the difficulty around age assessment in Nigeria, i.e. mostly unknown. Taking into account such uncertainty, the median age (on hospital admission) from their available hospital-based information was 28 years (1).

1.4.2.4 Illiteracy as risk factor

Onolemhemhen from Nigeria showed that obstetric fistula patients had less education, were of lower socio-economic status and were smaller in stature, but there was no difference among the groups in age at marriage and age at first delivery (98).

In most observational studies reviewed, illiteracy and short stature were found to be a risk factor for fistula formation (89,98,105). This is supported by recent study from Addis Ababa Fistula Hospital which documented association of illiteracy with longer duration of labour and more stillbirths. (Odds ratio (OR) 1.6 [1.2–2.2] and 2.5 [1.7–3.7], respectively) (3). Other reports from Ethiopia and Zambia also indicate that educational status and height of women were significantly below the national averages (3,101). Most observational studies (case series) also documented the fact that a great majority of women with obstetric fistula who were operated were illiterate (3–4,73).

1.4.2.5 Low stature as a risk factor

Low maternal stature was also regarded as a marker for a narrow pelvic cavity, and studies related maternal short stature to obstructed or prolonged labour and higher rate of operative deliveries (106–109). However, women of the same height from different populations and social statuses might have different risks, hence the obstetric significance of a particular height was said to be related to the woman's own ethnic and geographic background (96).

The few observational studies that looked into potential risk factors of obstetric fistula did confirm the association of height and some of the above-mentioned parameters to obstetric fistula formation, although guidelines for reporting epidemiological studies were not fully followed.

A case control study by Melah *et al.* indicated early age at first marriage (average 14 years), short stature (average height 146.2 cm) and illiteracy (96.3%) as major risk factors; and low social class, lack of gainful employment, failure to book for antenatal care (93.7%), and rural place of residence (95%) as potential factors associated with acquiring the fistulas (105).

Supporting height as a risk factor is data from another observational study by Sokal D *et al.* 1991, which measured the height of 1,733 women as they left the maternity services in Ouagadougou and recorded the type of delivery. Women less than 155 cm tall were 4.9 times more likely to have a caesarean section delivery (108).

A case-control study in Bangladesh with 132 cases and 150 controls found that a higher percentage of women with fistula had smaller foot-size and height (110). Over 60% expressed fear of an unhappy conjugal life, embarrassment in social life, a constant sense of impurity, and 87% were limited in religious activities because of the condition (110).

Meta-analysis by Dujardin and colleagues showed a significant and universal association between short maternal height and an increased risk of caesarean section for cephalopelvic disproportion, however, its sensitivity, specificity and predictive value were discouraging (111).

Several case series describing the characteristics of fistula patients have documented the short stature of women with obstetric fistula: average height 149 cm (73,79), 68% under 150 cm (76,100), average height of 148 cm (93,101), and 70% under 156 cm (75). Muleta *et al.* showed that the average height of 2,157 fistula patients in Ethiopia was 152.7 cm, significantly lower than the population average of 156.5 cm, also when broken down to age layers (3).

Potential risk factors reported from the few available observational studies are summarized in **Table 4**.

TABLE 4 Summary of potential risk factors on obstetric fistula formation from available observational studies

| Author | Major Risk Factors | Sample Size |
|--|---|-------------------------------|
| Ampofo <i>et al.</i> , 1990 (89) | Short stature (P=0.001) Younger age (P=0.001) | Cases = 241 Controls = 148 |
| Islam <i>et al.</i> , 1992 (110) | Smaller foot size Short stature | Cases = 132 Controls = 150 |
| Onolemhemhen <i>et al.</i> , 1999 (98) | Short stature Illiteracy Low socio-economic status | Cases = 50 Controls = 50 |
| Melah <i>et al.</i> , 2007 (105) | Early age at first marriage Short stature Illiteracy Low social class Rural location Lack of prenatal care | Cases = 80 Controls = 80 |

1.4.2.6 Male sex prevalent among index births

Reports indicate a dominance of male fetuses involved in labours ending in obstetric fistula formation (3,75–76). In the study from Ethiopia, male fetuses were involved in 77% of these labours, and these boys had a higher stillbirth rate compared with the girls, 91.9% (89.3–94.5) vs. 78.9% (75.1–82.7) (3).

Summary points

- Although difficult to ascertain cause, reported causes of genital fistula in developed countries are different from those from low resource countries
- While genital fistula of surgical origin is predominant in developed countries, obstetric fistula is a major problem in low-resource settings
- This basic difference in the cause of fistula in these two groups of nations has led to a divide of sorts between surgeons from these two different communities and this needs to be recognized and addressed
- Poverty is the underlying problem for obstructed labour and resulting obstetric fistulas
- Illiteracy and short stature are reported potential risk factors by most of the available observational studies, although the reporting of these studies is not strong
- Young age at marriage or first delivery as a risk factor is non-conclusive (available reports are controversial)
- There is no strong evidence to implicate parity as risk factor with an inconsistent range in the proportion of primiparous women with obstetric fistula. There is no clear data as to whether there is a difference in uterine activity among primi- and multiparous women during obstructed labour
- There are several other socio-demographic factors implicated as potential risk factors, however without strong evidence

1.5 Impact and Consequences of Obstetric Fistula

Very few studies examined impacts and consequences of obstetric fistula systematically (112). As almost all studies are case series and based on short-term follow up after surgical repair, strong evidence is lacking on the impact and knowledge remains limited about long-term prognosis following surgery, and therefore about the long-term contribution of fistula repair to quality of life improvement.

It was repeatedly documented that obstetric fistula leaves a woman with uncontrollable leaking of urine and/or feces from her vagina. Untreated, fistula leads to debilitating health problems, continuous wetness and odour, and the stigma surrounding the condition.

Besides incontinence to urine and or feces, reported impacts of obstetric fistula are extreme (85). Women reported suffering from genital sores, skin lesions, irregular periods, exhaustion, anxiety and depression; and even the inability to walk normally (most likely due to foot drop), foul smell of urine, infertility and amenorrhea (85,99). Wall (1998) under his article entitled “Dead mothers and injured wives”, explained the suffering as follows: “The affected woman suffers from a continuous and uncontrollable stream of urine or feces coming out of her vagina. This is both a physical and a social catastrophe. No escape is possible from the constant trickle of urine, the constant ooze of stool, 24 hours a day. These women become physically and morally offensive to their husbands, their families, their friends, and their neighbours (29,112). Indelibly stigmatized by their condition, they are forced to the margins of society, where they live a precarious existence.” (29).

Reports from pre-repair case studies and short-term follow-up after surgical repair emphasizes the severe social and psychological adverse effects such as stigma and social isolation; marriage breakdown; worsening of poverty; malnutrition, and severe depression (9,98).

1.5.1 Stigma, social rejection and psychological changes

In some countries, qualitative studies were undertaken to better understand the societal perception and stigma about obstetric fistula (113–114). Bangser *et al.* (85) found that 67% of the women in Tanzania and 99% of those in Uganda experienced isolation. The patients either withdrew from their communities due to shame or were isolated by others as a result of the stigma. Obstetric fistula represented a significant stigma for patients in Niger (113) and Malawi (114).

Different studies described the perception of rejection of fistula patients by the society. Studies in Nigeria reported that 53% of the women perceived themselves as rejected by the society (90,115). Many other studies quote different level of social rejection and isolation (29,73,76,110,116).

Often women with fistula might receive support in terms of food and shelter, but are segregated in the compound and are reported to sleep on their own, eat on their own and were not allowed to cook for others (2).

FIGURE 4

Young primiparous woman with obstetric fistula from North Gondar zone in Ethiopia, divorced and a social outcast.



Kelly describes the plight of social isolation when he suggested first treating the blindness of a blind patient with fistula, she replied, “Cure my fistula first. If I am blind people will sit with me and talk to me, but no one will come near me because I’m wet and I smell” (88). The reduction of stigma remains a major challenge for public health programs for fistula (117).

Fistula patients were considered to have brought shame and dishonour to themselves and their families; a patient from Niger stated the level of dishonour as follows “I was the mockery of the village, people run away from me because of my odour” (113). Women with obstetric fistula, when they manage to sustain their marriage, often lose any other form of support (115).

Obstetric fistula is confused with a venereal disease by some, or regarded as a curse or punishment from God, views which are likely to contribute to moral stigma (29,118). In Burkina Faso, women with fistula were deprived of timely obstetric emergency care because those who anticipate childbirth complications were assumed to be guilty of adultery. Some reports indicated that society blames women for the condition, and some women even blame themselves, and this might add to further social stigma encountered (29).

About 33% of fistula patients in Nigeria were reported to be psychologically depressed, and an additional 51% were bitter about life (115). A qualitative case study of 53 VVF patients in Northern Nigeria examined psychological effect, anger, depression, and disappointment with life. The majority reported loss of self-esteem, and psychologically, they experienced stress and anxiety (119). Over

54% of these women reported suicidal ideation (84,118,120). In a hospital-based observational study of the mental health of fistula patients in Ethiopia and Bangladesh, women with fistula were found to be more likely than the controls (female hospital workers) to screen positive for probable mental health dysfunction: 97% (66/68) and 32% (9/28), respectively (121). Another study investigated psychosocial consequences of obstetric fistula among treated and untreated fistula patients identified through a national survey in Ethiopia (118). While treatment improved the women's family and social lives, some health, social, and sexual problems persisted. Depression was an issue, even for treated women (118).

1.5.2 Marriage dissolution and partner rejection

Studies on marriage dissolution due to obstetric fistula were commonly reported (2,71,84–85,99). Many of these women were abandoned or divorced by their husbands, particularly when it became clear that the fistula persisted (2,71,85,99). The proportion of women abandoned by their husbands after obstetric fistula formation is reported to range between 14% in Zaire and Nigeria, and 15% in Zambia, to over 90% in Asia (53,71,122–123). About 25% women with fistula in Tanzania and 52% in Uganda were divorced, with almost all the separations resulting from their condition. Of the 20 women who were unmarried when they sustained fistula, 69% in Tanzania and all the women in Uganda remained single (85).

Often married women with fistula are sent back to their parents' home until they are cured, were not allowed to cook food (2,119), not allowed to participate in social events and not allowed to perform religious rituals (2,122). Ahmed and Holtz's meta-analysis showed that about 36% (95% CI: 27%–46%) of women were divorced/separated after developing obstetric fistula (112). The meta-analysis found that on average, 85% of these women lost their babies; however, other reports indicate that fetal loss can be as high as 95.5% (121).

Clearly, sexual and reproductive factors might have played a major role as a reason for abandonment by husbands. A study in Bangladesh examining the psycho-social consequences of obstetric fistula, reported that 33% of women claimed to have difficulty maintaining sexual relationships, 45% had delayed orgasm, 59% reported reduced frequency of coitus, and 52% of the husbands expressed loss of sexual pleasure (110). These findings are not surprising given the nature of the problem, and because vaginal stenosis might have resulted from obstructed labour and the subsequent fistula (3,9,73,84).

Infertility and loss of the child may be additional major components in the overall burden of obstetric fistula and its role in marriage dissolution. Stillbirth has been reported in up to 95% of neonates born to women with obstetric fistula (76,84).

Several studies reported that a large proportion of women with fistulas experienced amenorrhea at the time they were evaluated for care (29,84,99–100,124–126). However, none of the studies reviewed attempted to differentiate between postpartum amenorrhea and secondary amenorrhea.

Miscarriage after fistula is also reported to be high (127). The importance of having a child in order to sustain the marriage has been reported in a study in Zaria, Nigeria that brought attention to the fact that living children may reduce the risk of separation and divorce (2).

Another factor that might play a role in marriage sustainability is economic-related. A study undertaken in Addis Ababa found that women who owned property of value were less likely to be divorced by their husbands (73).

Some other reports however, indicate that despite decreases in sexual pleasure, or stigma and criticism from friends and family, some men remain with their wives, even in a community where divorce is common and acceptable (114). However, what encouraged these men to stay with their wives was not explored. It is also noteworthy that some women may successfully remarry, even with full disclosure of their condition (114).

1.5.3 Economic aspect and impoverishment

Poverty also deprives women suffering from fistula from timely and appropriate treatment.

A study from a hospital in Zaria, Nigeria, indicated that over time, fistula women become a burden to their families. The family support in paying hospital fees dropped drastically over time. Of the long-term patients, 19% recalled that their husbands paid the fare on their first visit, but only 8% for subsequent attendance (2). Facing familial and social rejection, and unable to make a living by themselves, many women with fistula live for years without any financial or social support (85). Approximately 85% of women with obstetric fistula said that fistula rendered them unable to perform household chores, work on the farm, or engage in other income-generating activities and their income deteriorated (85). Many explained that they fell into extreme poverty. The study carried out at Addis Ababa hospital reported that 39% of women were dependent on relatives for food, and 22% had begged or lived on donations (71).

1.5.4 Post-surgical improvements in quality of life

Although most of the reports were from case series, and the methods in these studies were of too low a level of strength to give strong conclusions, a sizable proportion of women were said to be returned to their husbands or got remarried after the treatment (90). Since the long-term follow up of patients was rarely undertaken and reported, the extent of reunion with husbands and remarriage is unknown. Due to extensive damage and subsequent fibrosis, a sizable proportion of women reported gynatresia and dyspareunia after repair (9,84,118). After surgery, a significant proportion of women who were amenorrhoeic reported the return of menses (125).

A large number of women were said to become pregnant after the repair (17,125,127–128). The proportion of newborns with low birth weight (LBW) was reported to be lower among the women with repair, compared to the women without repair (20.3% vs. 37.3%).

Lower urinary tract symptoms were reported to be common after successful anatomical closure of urogenital fistulas (129–132). Surgical treatment of obstetric fistula was reported to result in marked improvements in mental health, and despite suffering from stress or urgency incontinence, women reported improved quality of life and social reintegration after fistula closure (132–133).

Summary points

- Very few studies have systematically examined the impact and consequences of obstetric fistula, and strong evidence is lacking on impact, and knowledge remains limited
- However it was repeatedly documented that obstetric fistula leaves women with many severe social and psychological adverse effects
- Women with fistula were more likely to screen positive for probable mental health dysfunction than the controls
- Studies show marriage breakdown and social rejection due to obstetric fistula (134)
- Women with obstetric fistula have been reported to fall into extreme poverty after the problem and poverty deprives them from timely and appropriate treatment
- Women detailed marked improvement in quality of life and social reintegration after fistula closure, however with some residual health problems

1.6 Access to Care and Health Care-Seeking Behaviour of Women with Obstetric Fistula

Women with obstetric fistula report delay or difficulty in accessing essential care services such as emergency obstetric and obstetric fistula care services, mainly because of the long distances to reach care, poor transportation networks, lack of money, and because parturition is regarded as something that can be managed at home (2,14,47,73,76,91,135). Some of these women attributed obstetric fistula to God's curse, somebody's sin or evil spirits.

Only 21.1% of 899 women with obstetric fistula in Wall's series sought care after being in labour for about 24 hours; 97% of 91 women in Ndiaye's series had labour that lasted for more than 24 hours and 23.5% of 14,286 women with obstetric fistula treated at the Addis Ababa Fistula Hospital in Ethiopia had not given birth at the end of the 4th day during their index deliveries (3,76,135).

The proportion of fistula patients who accessed health institutions, for delivery, ranges from 8% in Kullima's series to 90% in Holme's series (1,8,14,21–22,33,71–73,75–76,79,93,99–101,135); in Ijaiya's series 33 (89.2%) reported to have had poorly supervised deliveries, however, there is no clear description of supervision where, what and by whom (21). In most of these women that accessed health care services for unrelieved obstructed labour, it had already caused damage to the mother and the fetus (8,22,47,76,79,94,98). Traditional birth attendants were called, local healers were consulted and local drug shops were visited before the decision was made to use modern health care services (47).

The average time lost before the decision to visit a health institution for obstructed labour (for those women accessed through community survey) was three to four days and for some of these women in rural Ethiopia, the difficult journey to a health institution with comprehensive emergency obstetric care services took as long as 48 hours (47,118).

The only case control (observational) study published, examined the hypothesis “vesicovaginal fistula patients have less contact with the orthodox health care system and prefer the traditional forms of maternal care compared to non-vesicovaginal fistula women” showed no substantive difference between VVF patients and non-VVF women in their utilization of both the orthodox health care services and the traditional forms of childbirth (98). The data suggest that both groups of women preferred the traditional health delivery system and only when the VVF patients experienced obstructed labour and when the obstruction went unrelieved, they ended up at the hospital, as an emergency case. The control group had no complications and therefore delivered at home with a traditional birth attendant (98).

Reported average duration of labour among women who had obstetric fistula ranges from 1.6 days (38 hours) to 4 days (1,18,33,47 71–73,79,90,99,135). Uniform in all these reports is that there is no description of the method used to characterize (define) the onset of established labour (1,3,73,76,105,135). However, the experience of women in obstructed labour and the pathologic defect observed among fistula patients support the story of the long suffering experienced by these women in labour.

A number of obstacles have been reported as constraints that prevent the timely access to emergency obstetric care services during index delivery, and include geographical distance, financial constraints, lack of family support, wanting to try traditional remedies first, perception of childbirth as a natural event, lack of permission, insufficient information about facility-based delivery, and fear of bad treatment by staff (3,35,73,76,85,87,101,105,135–136).

Delay in seeking medical care is as equally important as lack of good quality services in resource-poor settings where women commonly access and receive poor quality delivery and postpartum care due to the lack of a facility with essential EmOC services; lack of equipment, supplies, medications and severely limited human resources (8). Most literature reports institutional deliveries ignoring the capacity of health institutions visited and the interventions done to relieve the obstruction. Based on a few reported caesarean section rates, the percentage of caesarean deliveries performed, to end an obstructed labour that caused a fistula, varies from 6.7% of the 1443 women in Tahzib’s series to 50.2% of the 259 women in Holme’s series (8,13,76,78,99,101,135). Among 116 women interviewed at the Addis Ababa Fistula Hospital, 9 women (7.7%) had hysterectomy for ruptured uterus from neglected obstructed labour (78).

Women who could access fistula care services are those who had information and those who could overcome financial, social and geographical constraints (8,47,85,114). A report from Nigeria indicates that women travel distances up to 1,000 miles for fistula treatment, and the average delay was 61.5 months (1). Unreachable patients often remain inaccessible (8,114); those women who did not seek surgical repair but were accessed through community surveys explained that this was largely because they could not reach or afford the limited services available, did not know where to go, or were unaware that repair was possible (8,47,85,118). According to community- and facility-based

surveys in Tanzania and Uganda, the median length of time living with fistula for women recruited at community level was five years, compared with one year for women recruited at facilities (85). Women with a longer duration of suffering with fistula also had a longer duration of labour (8).

The average number of years of suffering for women, who accessed fistula care services, ranges from 8 months in a series of 14,829, from Ethiopia, to 5.3 years in a series of 80 patients in Nigeria (3,47,101,105). However for those could not access fistula care services and were identified through community surveys, the average time of suffering with the problem was eight years in rural Ethiopia and five years in Tanzania/Uganda (47,85).

For those women who accessed health institutions, their families expended significant amounts of money and time to access treatment, and funds were frequently raised by selling land and livestock (85).

All 41 cases reported from South Africa had sought care by 4 months, but about 73% of 899 women in Nigeria, and 21% of 14,928 women lived with obstetric fistula for over 12 months before seeking fistula care services (3,76,137). Those women with either a VVF alone or in combination with RVF were seen earlier than those women with RVF alone (5).

The proportion of women with obstetric fistula who attended antenatal care (ANC), during index delivery, ranges from 10% to 84% (3,76,85,105). The report from East Africa, which involved participants from Tanzania and Uganda, reported that 84% of the women said they had attended at least two antenatal care visits, but indicated that there were no hemoglobin tests, blood group assessments, urine analyses, syphilis screening, or voluntary counselling and testing for human immunodeficiency virus (HIV). In Tanzania, only 53% of the women reported being weighed, in Uganda, 31% of women reported receiving immunization services. Less than 10% said that they had had their blood pressures checked or were weighed and only 15% reported that the health worker listened for the fetal heartbeat. These women said they were given only limited explanations as to why they should deliver at a facility (85).

Moreover, access to a health institution was reported to be a major problem for fistula patients, mainly because of the long distances to reach care, poor transportation networks, lack of money, perception that childbirth is a natural event, lack of family support, lack of permission, wanting to try traditional remedies first, insufficient information about facility-based delivery, and fear of bad treatment by staff (73,85).

Summary points

- Reports on access to health care services rarely differentiate between lack of health-seeking behaviour and lack of service
- Most reports are descriptions of women's experience and difficulty accessing essential care services
- Reports on the duration of labour are based on women's self-assessment of the time of onset of active labour, which might be variable and might not be precisely known (138)
- Very few reports indicate interventions made to overcome the obstruction of labour
- Access to a health institution was reported to be a major problem for fistula patients, mainly due to long distances, poor transportation, lack of money, lack of support and permission, insufficient information, and fear of poor quality care

1.7 Conclusion and Recommendations

Empirical and reliable data on the epidemiology of obstetric fistulas are limited. However, due to growing interest in addressing the issue, a number of recent publications on the topic have appeared, though most are still low-level evidence. Most publications are based on case series, with some case-controlled studies, although with various levels of methodological strength (level 3). Only one community-level prospective study on the incidence of obstetric fistula (level 2) has been published. There are a few facility-based prospective studies (25–27,32), and retrospective record-reviews among studies with level 3 evidence have to be used to estimate the incidence range of obstetric fistula. Similarly, for prevalence estimates, there are a few available community surveys and very few case-control studies (level 3) have been used to analyze frequently reported risk factors. Expert experiences and critical views or opinions have had to be included, in view of the absence of better quality data (level 4).

1.7.1 Magnitude and distribution of obstetric fistula

Reliable research on the burden of disease is lacking (139). Representative data to make a global estimate of the prevalence of obstetric fistula does not exist and validated symptom-based case definitions should be established to obtain multi-country representative data to enable the global estimate of the burden of the problem. Qualitative validation studies are necessary to determine the sensitivity and specificity associated with this kind of question in national health surveys; however, there will always be some level of problem with precision in any attempt to measure the prevalence of this particular morbidity using self-reports. Pelvic exams are unlikely to be introduced into major nationally representative surveys, given the expense and the lack of trained local health care providers who are available and qualified to identify VVF and RVF. The development of a validated symptom-based diagnostic tool is highly recommended. The Data, Indicators, and Research subgroup of the larger International Obstetric Fistula Working Group (IOFWG) met in October 2006 and adopted an approach to survey-based data collection for obstetric fistula. This is available in the DHS analytical study by Johnson and Peterman (43).

Prevalence estimates obtained from national community surveys were more consistent across studies from Asia, West Africa and East Africa. There is a need for more national level community-based prevalence studies from different regions of developing countries using validated survey methodology using validated symptom-based instruments or case ascertainment by clinical evaluation.

In developing countries, a vast majority of women deliver at home and institution-based study results may not be generalized to the entire population. Available facility-based incidence estimates are inconsistent and biased. There is only a single community based prospective study available on the incidence rate of obstetric fistula for West African countries. Prospective longitudinal community based studies are strongly needed to estimate the incidence of obstetric fistula and to describe the proportion of different forms of obstetric fistula and the risk factors associated with these different forms.

The geographic coverage of studies on obstetric fistula is limited to only a few countries. There is a need for more epidemiological research from different countries and continents of developing countries, and a need for good documentation and reporting of the very few cases of obstetric fistula from developed countries, to enable the precise knowledge of the distribution and magnitude from a research perspective. This should include the prevalence of different types of obstetric fistula including the prevalence of anal sphincter damage from obstetric causes; the issues of anal sphincter function in obstetric fistula patients have still to be addressed.

1.7.2 Causes and potential risk factors

There is insignificant evidence on the influence (association) and level of association of different demographic, social, economic and cultural parameters, as potential risk factors and protective factors for obstetric fistula. There are few studies that quantify the strength of associations using relative risks and odds ratios with confidence limits.

There is a need for more observational studies (analytical studies) with advanced epidemiological analyses of risk factors (multivariate analysis) controlling for potential confounders. Reporting of such observational studies should follow observational research-reporting guidelines. The STROBE (STrengthening of the Reporting of OBservational studies in Epidemiology) is a checklist of points that should be included in observational study articles and the use of this checklist is recommended (140).

There is very little documented evidence about the actual labour causing the pelvic damage and corresponding fistula, and no clear descriptions of uterine activity during obstructed labours. There is a need for high quality basic research and the need to link clinical observations and intervention studies to the laboratory sciences. With respect to the pathophysiology of obstructed labour, there are scientific questions which need to be addressed, and this might shed light on the dilemma of objectively ascertaining whether the fistula occurs due to obstructed labour or from interventions made to relieve the obstruction.

An observational study examining normal patterns of urination in labour could illuminate the significance of urination difficulties and its association with postpartum consequences.

The relationship between low-income or “unattended” delivery and the occurrence of obstetric fistula seems not to be universal. Although poorly documented, African countries and Southeast Asia appear to be more afflicted than disadvantaged populations in the Americas or other parts of the world, suggesting other factors being in play (e.g. ethnic background, nutrition). This is an area recommended for further exploration.

1.7.3 Impacts, consequences and health-seeking behaviour

There is little evidence on the level of association of the various impacts or consequences mentioned with the problem (obstetric fistula). There is a need for more observational studies on the issue and a need for the reporting of these studies to follow the standard reporting guideline (140).

Fistula patients, incontinent to urine and/or feces, are often ostracized by the family and community, and their presence in the household or community might not be reported by others, hence underestimating the magnitude of the problem. Prevalence or incidence rates in obstetric fistula patients might be sensitive to the perception and attitude of the respondent about obstetric fistula. The stigma that can surround the condition might preclude accurate estimates of the prevalence and incidence of the condition. Hence, the data collection instruments need to have that power to persuade and convince respondents (objective and benefits-oriented tools are essential), so that accurate reporting occurs.

This review has indicated that the occurrence of obstetric fistula is a reflection of a variety of inadequacies, as the women had been in labour at home for days before reaching health institutions, lacking information, transportation, support, economic resources and appropriate health care services. However, observational studies comparing the situation of other women without obstetric fistula from a similar community are hardly available. Hence, there is a need for observational studies addressing this issue.

1.8 References

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C2

Vesicovaginal Fistula Prevention

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“If the people see the service as meaningful to their lives; if it is compatible with their norms and values, if they feel a sense of ownership, and support from people they respect, then there will be an incentive and motivation to maintain it.”

– Paul Basch, 1999. (1)

2.1 Overview

Obstetric vesicovaginal fistula (VVF or OF) is a complication of prolonged, obstructed labour in childbirth. The extent of the problem in affected countries has yet to be fully documented, as these data are either not collected by the health system or patients may fail to seek treatment. Vesicovaginal fistula is the commonest of the various types of obstetric fistula, the others being: recto-vaginal fistula (RVF) and urethro-vaginal fistula (UVF). Preventing VVF is part of a larger goal of safe childbirth—safe for the mother, and safe for the child. It is a “disease” of poverty, a clear marker of the failure of political, social and health systems to protect and promote women’s health and their health rights. In developed countries with strong medical infrastructure and social support for prenatal care, labour and delivery, VVF is only seen as an iatrogenic complication of hysterectomy or other pelvic surgery, or of radiation for cervical cancer. Prevention is ultimately linked to prevention of maternal mortality from all causes, and also linked to prevention of infant and child mortality. VVF is largely seen in poor countries and regions where access to appropriate prenatal and obstetric care and family planning are limited, including rural areas and dense population centres marked by extreme poverty (2).

The Millennium Development Goals (MDG), adopted by the UN to improve global health and development, set an agenda to reduce maternal mortality by three quarters between 1990 and 2015. The particular goal addressing maternal health is Goal 5, also known as MDG5. In wealthy nations, the risk of maternal death in childbirth is 1:5,600 or less. Yet, in many countries in sub-Saharan Africa, the risk of mortality is as high as 1 in 30 (3). Health care and maternity care is linked to the availability of financial resources to the individual, community or country; as these improve, risk of VVF diminishes. Therefore, it is useful to look at components of prevention broadly in addition to looking at specific factors that can mitigate risk for a particular woman. One key to prevention is family planning. In wealthy regions, family planning is available by choice to individuals; in others, like China, it is actively encouraged or enforced. However, in the years between 2000 and 2008, external aid for family planning in sub-Saharan Africa decreased substantially and is now lower than it was in 2000 (3).

2.2 Why Prevention?

From the medical and public health point of view, prevention or mitigation of disease reduces the overall burden of pain and suffering, not just to the patient herself, but to her family and to the entire community. In many parts of the world, history has shown that improvements in systematic functionality reduce the incidence of maternal death and disability. Systemic improvements also address interlocking social and economic inequities such as the low status of women, lack of education for girls, early marriage and pregnancy, malnutrition, poverty, inadequate health and transportation infrastructure and harmful traditional practices such as female genital mutilation/cutting (FGM/C) (4). “Safe Motherhood” and the systems that support it can be considered to be a human right. It can also be considered as an economic policy and as an element of security strategy.

Some components of public health practice, such as campaigns to raise awareness about the special nutritional needs of female children to prevent chronic malnutrition and to improve the physical maturity of young mothers, are part of holistic prevention strategies. It is useful to review them since sustainable improvement requires a systems change, not just action at an individual or local level. The cost benefit of prevention can be measured and has been quantified in terms of the DALY (5), or disability-adjusted life year. In terms of prevention, the measure is the cost per DALY averted. This measurement allows policy makers and funders to consider the relative allocation of limited resources to programs that actually have measured benefit. Even problems that are ultimately resolved by surgery can be addressed in terms of multilevel prevention.

Vesicovaginal fistula can be considered to have both direct and indirect causes. Indirect causes of obstetric fistula are: poverty, poor social status, long distance to medical care, high levels of illiteracy, and poor or lack of public-health education. The deficiency of quantitative information about these causes is a major obstacle in advocacy, coordination, and the implementation of prevention strategies. The formation of national policies is a major step forward because such policies create a framework for data collection and the strategic implementation of care. Moreover, they lay a foundation for accountability at all levels.

Direct factors that predispose a woman to prolonged and obstructed labour include malpresentation of the fetus and cephalopelvic disproportion. Malpresentation can occur in any woman, but it is more frequent in grand multiparas (a woman who has given birth five or more times) with lax uterine muscles. Cephalopelvic disproportion is a condition where a baby’s head or body is too large to fit through the mother’s pelvic outlet. The consequence of obstructed labour is ischemia of tissues of the birth canal and adjacent organs, with subsequent ischemia and sloughing of tissue. In developing countries, 90% of obstetric fistulas are caused by prolonged obstructed labour (6,7).

A comprehensive fistula prevention program requires a multilevel approach (8) involving the many stakeholders in the community. National programs for emergency obstetric care (EmOC) have many of the same components. The character of national and regional strategies must then be more finely tuned to the geographic, demographic and economic needs of the region.

FIGURE 1

Birth rate per 1,000 population. Data from CIA World Fact Book, 2009. In deVries CR and Price RR, Global Surgery and Public Health, A New Paradigm. 2010 (8). p. 15, Fig. 1.4.

Illustration used with permission from Intermountain Healthcare.

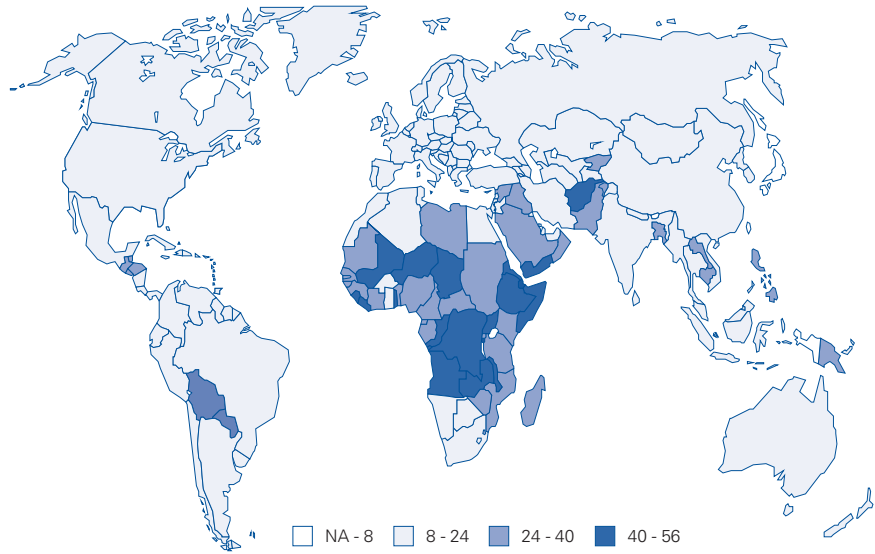
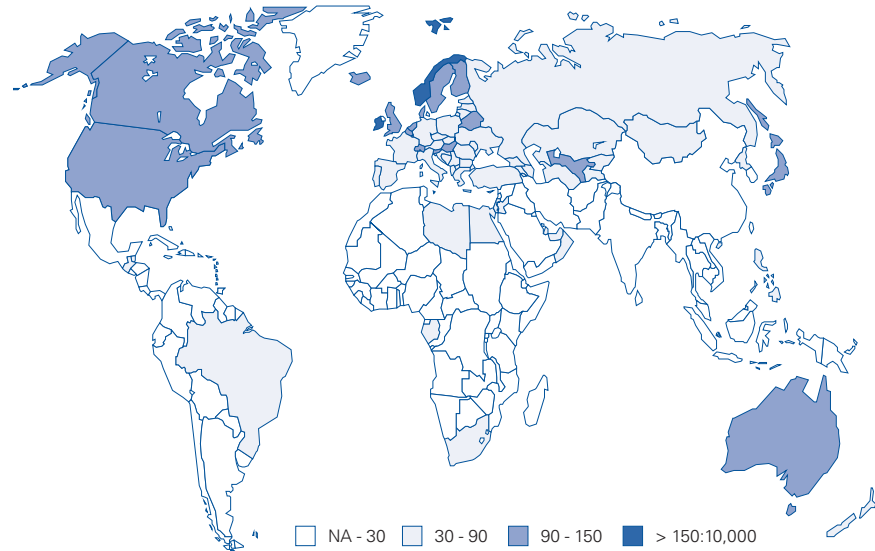


FIGURE 2

Nurses and midwives per 10,000 population. Data from WHO 2009 World Health Statistics in deVries CR and Price RR, Global Surgery and Public Health, A New Paradigm. 2010 (8). p. 15, Fig. 1.5.

Illustration used with permission from Intermountain Healthcare.



2.3 Categories of Prevention

Prevention strategies may be considered in public health terms as primary, secondary, or tertiary.

Primary prevention addresses many indirect causes which are, essentially the “root causes” of VVF/RVF. It attempts to reduce or eliminate the risk of the disease.

Secondary prevention attempts to limit the severity of the disease by catching it at its earliest stages.

Tertiary prevention is aimed at mitigating complications of existing disease.

TABLE 1 Categories of Prevention Strategies: The Haddon Matrix

| | Primary | Secondary | Tertiary |
|------------------------------|--|---|--|
| Vesicovaginal Fistula | Nutrition Education Delayed marriage Waiting houses Training midwives Roads, ambulance Communication | Partographs (Symphysiotomy) Caesarean section | Repair VVF Physical/Social/Economic Rehabilitation |

An example of primary prevention is education. Education of girls and women is known to be associated with improved economic status and improved infant survival at the household level. Strengthening the education system to benefit women and girls is a long-term goal in countries where fistula is prevalent. In most African countries, for example, the education of males takes priority. In some, paradoxically, women have even perpetuated their own subordination. Here, the enemies of women’s education can be their fellow women, including traditional birth attendants (TBAs). Many women have been socialized to pass wariness for education on to their daughters (9). Another primary strategy that is more temporally linked to parturition is the “waiting house”. Waiting houses are homes or houses close to birthing facilities where pregnant women await the onset of labour. They are particularly helpful for first-time mothers and women who have been identified to have a high risk for complications of labour. Then, once labour has commenced, a partograph can be used to monitor progression of labour by documenting specific timelines and events. They can help to identify problems during labour and can supply data for analysis of complications.

2.3.1 Haddon matrix applied to vesicovaginal fistula

Prevention can be further broken down to identify sub-factors and to isolate objectives of intervention. The Haddon matrix is one way to do this. First developed as a tool to analyze root causes of road traffic injuries, the Haddon matrix has become a useful tool for the study of causes of other injuries. Applied to VVF, such a matrix might look at local and regional prevention efforts, but might also include international and global factors and strategies (10). For example, the United Nations Population Fund (UNFPA) has taken on the challenge of reducing the burden of VVF with its Maternal Health Thematic Fund, directed to support national programs for MDG5. Complementary aid funding has been assigned to the UNFPA Global Programme on Reproductive Health Commodity Security and the Campaign to End Fistula (11).

TABLE 2 The Haddon Matrix Applied to Vesicovaginal Fistula (VVF)

| Factors | | | | |
|------------------------------|--|--|--|---|
| | Objectives of Intervention | International, National, Regional | Community | Hospital |
| Primary (Pre-event) | Recognizing factors associated with birth complications including, mortality and VVF | Economic Aid Roads Education Communication Electricity supply Policy/Media Field surveys Medical staff training | Maternity insurance Marriage customs Prenatal care Midwife training Engagement and education of traditional birth attendants | Adequate facility, equipment, staff |
| Secondary (Event) | Recognizing\ Addressing individual risk | Transportation Field Surveys | Maternity waiting houses Partograms Low gynecological age, Grand multiparity | Caesarean section, (Symphysiotomy) Foley catheter drainage |
| Tertiary (Post-event) | Treatment/ Re-integration | Media Campaigns | Microcredit/ Microenterprise | Fistula surgery |

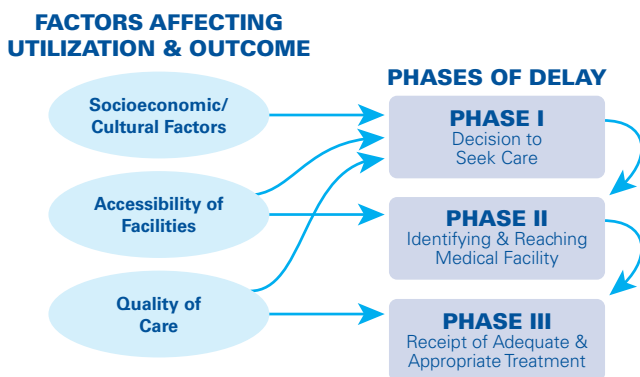
2.3.2 The three phases of delay

The Haddon Matrix has the advantage of providing an overview of strategies, but it does not convey a sense of urgency in time. The concept of “The Three Delays”, delineated by Maine (12), conveys, in a more dynamic sense, the sequential phases of delay that can be approached in preventive terms. In childbirth, from the onset of labour, there is a limited time during which a mother and baby must begin the process of delivery, recognize a problem, and seek and find appropriate care. A woman becomes vulnerable to weaknesses in the system—at many levels during the course of labour. The delays can be depicted by the following schematics.

FIGURE 3

Three phases of delay (12).
deVries CR and Price RR,
Global Surgery and Public
Health: A New Paradigm.
2010 (8). p. 51, Fig. 2.4.

*Illustration used with permission from
Intermountain Healthcare.*



The three delays

In each country and community, there will be different socio-economic and cultural factors influencing the delay to seek care. They may include the need to obtain permission from a husband or male family member. There may be a community perception that only “weak” women need assistance with delivery and that “strong women” should be able to deliver without assistance. Once a phase I delay has occurred, phase II becomes more urgent. Road conditions, transportation and communication deficiencies may conspire to further delay a woman’s arrival at a hospital or birthing center. Lastly, there may be a delay in receiving adequate care due to lack of facilities, electricity, supplies, or staff. If the lights are out and there is no back-up generator or fuel, a caesarean section cannot be done. If there is no way to contact a doctor or medical officer because of a lack of telephone, or if the instruments have not been sterilized due to lack of staff, electricity or other factors, a timely operation might not be done. These delays disproportionately affect the world’s poor—especially, rural women.

The 1st delay: decision to seek care

A variety of factors can keep a woman from attempting to seek care at an institution. A woman’s lack of confidence in institutions, a traditional birth attendant’s competitive resistance to refer emergency cases, or a husband’s refusal to allow his wife to go to the hospital can all influence the decision to seek care.

In many communities, the hospital is considered the place where people go to die. Given that many people will go to the hospital only as a last resort when they have exhausted all other alternatives, this belief is partly self-confirming. Faith in hospitals also suffers when a community blames deaths occurring in the hospital on the institutions, while considering death at home as unavoidable. These prejudices and past experiences can colour a community’s faith in institutional competency and delay an individual woman’s decision to seek care.

In some communities, TBAs can be direct competitors to institutional service providers. Unless productively engaged in a skills-specific referral function, these TBAs may be less likely to refer in emergency cases. To do so might essentially admit to the customer (the woman in labour) that the TBA is not as competent as the competition (the hospital). These factors can drive TBAs, acting as the woman’s agents, to delay the decision to seek care. It can also happen that a woman and her TBA

agree on the need to seek care, but the woman's husband, acting as the woman's agent, refuses her permission to seek care. Cultural tradition, economics, and family dynamics can influence decisions that appear to be irrational to people of other cultural traditions (13).

The 2nd delay: arrival at a health facility

This delay is driven by distance, terrain and transportation availability. To find solutions to this delay, one might consider bringing women closer to health care facilities, such as waiting centres or "waiting houses". Another approach is to bring care to the patient. An East African non-governmental organization (NGO), the African Medical and Research Foundation (AMREF), has provided maternal care over great geographic distances for both elective and emergency surgery by providing on-site facilities, and using air transportation, in a model designed to provide coverage to isolated communities. (14).

The 3rd delay: the provision of adequate care

This delay is caused by institutional inefficiencies in predicting, preventing, diagnosing, and managing clear cases of obstructed labour.

The underlying causes can be unbalanced volume of service compared to need, poor management of health facility resources, and, sometimes, corruption.

2.4 Individual Risk

Although more women aged 20 to 45 give birth than women in the age group 10 to 19, close to 50% of all fistula cases occur in women aged 10 to 19. The majority of these cases are likely due to cephalopelvic disproportion caused by pelvic immaturity resulting from low gynecologic age and malnutrition.

Low gynecologic age: Gynecologic age is defined as chronologic age minus the age at menarche. During the first three years after menarche, a woman's pelvis is still maturing. A woman with a gynecologic age of less than three years has not yet reached pelvic maturity. First-time mothers in the developing world tend to have a lower gynecologic age than adolescent mothers in developed countries. Maternal death and disability can be broadly prevented in many of these cases by convincing community members of the importance of delaying pregnancy until a woman has reached pelvic maturity.

Malnutrition: Even in cases where a girl has aged beyond the danger zone of pelvic immaturity, chronic under-nutrition and malnutrition may contribute to a reduced likelihood of the woman having reached adult size by menarche.

Education: To most appropriately address individual predispositions, prevention of obstructed labour and fistula should begin very early in each girl's life. For example, campaigns to raise awareness about the special nutritional needs of girls to prevent chronic malnutrition and to improve the physical maturity of young mothers are part of holistic fistula prevention strategies (7). Other

recommended strategies include empowerment programs targeted at high-risk women and girls in schools and in the community. This approach can also address issues of substance abuse, poor dental hygiene and sexually transmitted infections (15).

Combined risk factors: In his study of individual risk factors for obstructed labour, G.J. Hofmeyer reviewed the effectiveness of certain promising approaches to reducing complications of obstructed labour (16). These included: measuring maternal height and shoe sizes, x-ray pelvimetry of the mother and the estimation of fetal weight. Hofmeyer discussed using external cephalic version, or turning the baby by applying external pressure at term, but not before, as an effective method of preventing obstructed labour. He stressed the importance of companionship and hydration and suggested that extremely low-dose misoprostol might be a method for labour augmentation but that further clinical research was needed. Though it is unlikely that x-ray pelvimetry will be widely adopted due to risks to the baby and the lack of availability of x-rays, other recommendations, such as the partograph (17), have been adopted by WHO as a standard for childbirth.

Hofmeyer considered caesarean section an essential technology that could be made widely available in conjunction with spinal analgesia, local infiltration analgesia and simplified surgical techniques. Hofmeyer has written that when caesarean section is unavailable, symphysiotomy may be life-saving for mother and baby. He notes the following advantages of symphysiotomy over caesarean section:

- Can be performed more rapidly
- Is simpler to perform
- Requires minimal equipment
- Can be performed by health workers without laparotomy skills
- Uses local analgesia
- Does not require an operating theatre or anaesthetist (but does require 6 weeks of bed rest, after the procedure, to prevent complications of an unstable pelvis)
- Does not carry the risk of a scarred uterus in subsequent pregnancies
- May be life-saving for the breech baby
- May be preferred in cultures in which caesarean section is viewed as a personal failure

The recommendation for symphysiotomy remains highly controversial and a strong evidence to support its use is lacking.

2.5 Measuring Burden of Disease

Successful programs require measurement of outcomes, which in turn require an understanding of the scope of the problem. An early attempt at estimating the global and regional burden of disease was made by the 1990 Global Burden of Disease (GBD) study commissioned by the World Bank (18). It developed the metric, the DALY (disability adjusted life year) to quantify the global burden of diseases, injuries and risk factors. These were updated in 2000, and recently updated again for GBD 2010, available in 2011. The first update, known as DCP2 (Disease Control Priorities-2), estimated that “Approximately one-third of maternal conditions, including hemorrhage, obstructed labour, and obstetrical fistulas, are surgical, and these represent 10 million DALYs, or 0.7% of all DALYs” (19). Yet, the calculations were based on limited data, and are conservative, based on a study in Bangladesh. The DALY estimates in this chapter are based on a single report from a 40-bed non-governmental hospital in rural Bangladesh in 1995 (20). Debas *et al.* noted that, “A caesarean section for obstructed labour was estimated at 10 percent averted risk for the infant and 0 percent for the mother. A caesarean for transverse lie was estimated at 90 percent averted risk for the infant and 90 percent for the mother.” (19)

A more recent analysis of the economics of care was presented at the Carter Centre, in March 2010, by D. McFarland (21), in an analysis of the economic burden of VVF in Niger. A study was done to establish the burden of disease, the costs to the health system of Niger, the number of DALYs that could be averted through preventive measures, and the cost to Niger’s government of the implementation of preventative measures. In Niger, an estimated 111,570 DALYs could be attributed to obstructed labour and fistula, or potentially 58.56 DALYs per case. The cost per DALY averted by caesarean section, including improving and equipping existing health facilities, was \$1.11. This is highly cost-effective, and in fact, less than the cost of other public health measures such as treatment for HIV/AIDS (US\$300–500 per DALY averted) or vaccines (US\$5/DALY averted). Neglected tropical diseases are estimated to cost US\$2–9 per DALY averted (22). Clearly, from the economic point of view, the cost for upgrading and implementing maternal care is a bargain.

2.6 Tools for Designing and Implementing Preventative Strategies

The “catalyst approach” to public health employs a method for rapid implementation of prevention practices. Community-based catalyst elements cost approximately two million US dollars annually for a 12-country effort in Africa, in one disease eradication program (dracunculiasis, or “Guinea worm”). It has been roughly estimated that catalyst elements of a program to rapidly reduce maternal mortality by supplementing ongoing longer-term solutions may cost on the order of five million dollars per year (excluding surgical intervention) for a similar group of 12 countries across Africa. For consortia of donor countries and foundations, such amounts are well within reach (23). Its pivotal concept is a community-based initiative with certain key components.

Key principles in the Rapid Prevention model are as follows: (24)

- 1. Key people** from a small number of organizations who “really care”: 5–10 total.
- 2. Data manager and program manager** for each country.
- 3. An organization:** 1–2 people with experience in epidemiology, to collect and analyze data. Need not be in country.
- 4. Resident country technical advisors.** These may be expatriates who work collaboratively but are funded from outside the infrastructure within which they work. They have no formal power, but are independent and committed.
- 5. International meetings:** Staff from countries and supporting agencies meet to present data every 6 months.
- 6. Annual program review:** Attended by representatives from all levels, from village volunteers to Ministry of Health senior leadership to discuss success, problems and ways forward.
- 7. Annual training and re-training** of village volunteers.
- 8. Network of supervisors.** Supervisors visit each village monthly, gather data, and visit homes. National staff visits at announced and unannounced times.
- 9. Transportation:** Can include bicycles, to boats. Annual funding for transportation of supervisors for 4–6 years, including replacement vehicles.
- 10. Course correction mechanism:** For improving technical tools and approaches.
- 11. Political mobilization.**

An additional requirement for this community-based program is the recruitment, training and participation of community volunteers. In order for them to be effective, the following criteria must be met:

1. Diagnosis by the trained volunteer must be generally as good as a physician.
2. Correct action by the trained volunteer must positively and clearly affect the clinical outcome.
3. The event must initially not be so rare that individual volunteers are unlikely to experience it or so frequent as to require almost full-time activity, thereby excluding the part-time volunteer.
4. The functioning system must provide annual re-training; regular supervision, monthly collection and analysis of data, timely re-supply of materials, and feedback on progress achieved against other districts, regions, countries, etc.
5. The issue must be important to people in the community, e.g. carry a high risk of death, handicap or suffering that “all” would wish to avoid.

2.7 Best Practice Examples: Projects That Work

1. Health and Development International (HDI), Niger

At the meeting for Obstetric Fistula Prevention as a Catalyst for Safe Motherhood: Successes and Opportunities, March 9–10, 2010 (25), preliminary data from 600 village volunteers in Niger using this program demonstrated a reduction in obstructed labour of 11 deaths in 2007, to 2 in 2008, and none in the interval between May 2008 and March 2010. Definitive statistical analysis of the project will be forthcoming in 2011. The basic strategy has been laid forth in an online publication, “Toolkit for Rapid Prevention of Fistula (23)”. The principal features of the toolkit are outlined above in the Rapid Prevention Model (24).

2. The Women’s Dignity Project, Tanzania

Tanzania conducted a fistula survey in 2001 that has provided a focus for national policy and women’s advocacy. It uses research on the incidence and prevalence of obstetric fistula to mobilize the community and to hold policy makers accountable for decisions in women’s health. The community is reached through drama, music, dance, TV, radio and ads on taxis. Policy makers, journalists and the general public are also reached through photo exhibits, seminars, and workshops. The project works in conjunction with the UNFPA Campaign to End Fistula (26).

3. The Barbara May Foundation in the Amhara and Afar Regions, Ethiopia

In order to address the “Three Delays” discussed above, the Barbara May network has developed and implemented the following schema (27):

Layer 1: 650 traditional birth attendants (TBAs) were trained and equipped to identify and refer high-risk women.

Layer 2: Waiting areas were built along the road where high-risk women could go to await delivery. These are staffed by midwives or skilled birth attendants (SBAs).

Layer 3: Emergency obstetric care (EmOC) is currently being provided at facilities adjacent to government health centres, but is staffed by expatriate volunteers.

The Barbara May program has experienced some limitations, such as poor acceptance of waiting areas, unsustainability of expatriate volunteers, and problems in the identification of high-risk pregnancies. Yet, the system has appeal because it addresses the significant regional geographic barriers and the lack of locally trained staff for EmOC.

4. Doctors Without Borders (MSF) program in unstable situations

MSF operates fistula campaigns and EmOC in both stable and unstable political circumstances worldwide. Their paradigm, reported at the Carter Center (28) is as follows:

Level 1: Prevention using EmOC and EmONC (incorporating neonatal care), technical support, establishment of referral and communication systems.

Level 2: Sensitization of communities, women, men, TBAs and leaders.

Level 3: Employment of Foley catheters for fresh fistulas, record and refer established fistulas for referral.

Level 4: Prevention of subsequent fistulas after successful repair through sensitization, follow-up, and maternity waiting homes. Waiting homes in close proximity to facilities capable of managing high-risk deliveries can help prevent recurrent birth complications including fistulas, in subsequent pregnancies.

5. HEAL Africa: the Safe Motherhood Program in North Kivu, Democratic Republic of Congo (29)

The prevention strategy in this community-based program involves community mobilization, training of local leaders and TBAs, raising the socio-economic status of women of child-bearing age through education, creating solidarity groups for insurance and mutual support, training health professionals, and equipping maternities and hospitals for partographs and C-sections. Interestingly, this program has found in surveys and interviews that most women in the Great Lakes Region preferred to deliver in a maternity service if it were available. Membership in solidarity groups increased the use of family planning and maternal medical care through maternity insurance schemes and advocacy. The training of traditional birth attendants appeared to positively influence referral to maternity centres. They found that armed conflict was the greatest barrier to improved health care in the region.

6. Birth preparedness and complication readiness, Burkina Faso

Piloted in Burkina Faso between 2001–2004, and reported by Moran *et al.* in 2006, a program was developed to reduce birth complications (30). Its key elements were massive sensitization of communities regarding the danger signs in pregnancies and the need for regular antenatal care by all expectant mothers. Participants were also taught prenatal planning for the location of delivery; transportation; and, how to save money specifically for taking care of oneself and family during the perinatal period.

In 2004, a cross-sectional survey with a random sample of respondents was conducted to assess the impact of this strategy. Of the 180 women who had given birth within a year of the survey, 46.1% women had a plan for transportation, and 83.3% had a plan to save money in preparation for childbirth. Women with these plans were more likely to give birth with the assistance of a skilled health provider, whereas previously, only 38.5% of the women gave birth with the assistance of a skilled provider.

7. Audit and feedback strategies, Malawi

Sometimes the act of collecting and reporting data can have a positive effect on awareness and action, even when no other specific intervention is attempted, and with resources already available. Audit and feedback strategies introduced in a number of health facilities in Malawi in 2005 showed that overall, there was a significant increase in the met Emergency Obstetric Care (EmOC), over a three-year period. Similarly, maternal mortality decreased significantly: from 250 per 100,000 women in 2005, to 222 per 100,000 women in 2006, to 182 per 100,000 women in 2007. During the same period, the case fertility rate decreased monotonically. The study suggested that audit and feedback strategies could improve the availability, utilization and quality of EmOC in countries with limited resources (31).

2.8 Future Goals for Prevention

As outlined above, strategies for implementation of maternal and child health require a comprehensive approach tailored to local conditions. The most cost-effective and socially acceptable of these involve strong community support, in the form of solidarity groups and local volunteers, along with the training of both skilled and traditional birth attendants, depending on the local customs and resources. The Rapid Catalyst approach can coalesce these and the district and national services with international support; while other infrastructural changes, institutional audit and feedback, improved medical staff training and educational opportunities for girls are developing, perhaps at a slower rate. Successful programs for Safe Motherhood share many of the same features. Both the Rapid Catalyst and the rights-based approaches have the additional ability to leverage international foundation and advocacy dollars in local and targeted programs that can have measurable outcomes over a 3–5 year period. They can be somewhat more nimble than policy-based approaches, particularly in poor countries.

Identifying and targeting components of the “Three Delays” will contribute to successful outcomes for obstructed labour, and will also benefit the other maternal complications as well; in addition to benefitting the infant and child, and ultimately, the community. The surgical prevention and management of obstetric fistulas ultimately are best embedded in strong social programs for public health and education. These programs will ensure sustainable improvements in the health of women and mothers.

2.9 Recommendations

1. National policies create a framework for data collection and the strategic implementation of care. They lay a foundation for accountability at all levels. National policies for maternity care should be developed for all countries whether or not VVF is a common complication of childbirth.

2. Solidarity groups, including village volunteers; and skilled and trained traditional birth attendants, should be developed for maternal care (C).

3. Girls, women and communities should be educated about normal and abnormal labour, and facilities such as waiting houses should be available for pregnant women at risk for complicated deliveries (C).

4. The components of the “Three Delays” need to be identified and targeted for each community where there is a high prevalence of complications of childbirth (C).

5. Birthing centres with the capability for caesarean section should be accessible and sufficiently affordable for women to use (C).

6. Funding should be made available to retain adequate trained staff for waiting houses and birthing centres (C).

7. Partograms should be employed to track the progress of delivery in order to identify problems and collect data (C).

8. Data collection by local, national and regional bodies should help to define the incidence of birth complications, and factors leading to the “Three Delays” (C).

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C3

Unmet Needs in Fistula Management and Training

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relationships
family
mother
strong
proud
education
normal
self-esteem
empowered
cured
continent
align
diagnose
status
interaction
better life
agents of change
participation
productive
gaining

3.1 Introduction

The unmet needs in fistula management and training are vast. In order to comprehend the scope of the problem, an extensive review of the literature was undertaken by members of this panel using several search terms, including: *obstetric fistula, vesico-vaginal fistula, recto-vaginal fistula, female, genital tract fistula, post-partum trauma, urinary fistula, training models and bladder fistulas*. The literature was extensively reviewed using the following databases: PubMed, Medline and other internet sources. The search terms used included *obstetric fistula, vesico-vaginal fistula, recto-vaginal fistula, female, genital tract fistula, post-partum trauma, urinary fistula, bladder fistulas, training models and education in fistula surgery*. On reviewing the literature, it was apparent that the quality of the studies varied widely – the levels of evidence ranged from level 2 to level 5. As a consequence, the grades of recommendations, based solely on the literature, could not exceed a Grade B. But this is not a simple field, and perhaps one needs to approach it from a different perspective.

In this chapter we will provide an overview of the current situation of unmet needs in obstetric fistula, including a perspective from the professional societies and an overview of training models and methodology.

3.2 An Overview of the Unmet Needs in Obstetric Fistula

In order for one to appreciate the unmet needs in obstetric fistula, one needs to understand the extent of the problem. The International Obstetric Fistula Working Group (IOFWG), set up by the United Nations Population Fund (UNFPA) in the early 2000, has been instrumental in developing a global initiative of mapping obstetric fistulas in the developing world. This has been done in tandem with the Fistula Foundation, Direct Relief International, UNFPA, the Geneva Foundation for Medical Education and Research (GFMER), EngenderHealth, Women and Health Alliance International (WAHA) and International Society of Obstetric Fistula Surgeons (ISOFS). In time, this initiative aims to provide information about fistula centres, activities and trainers across the globe, to identify service gaps, to help develop training for fistula surgery and to gather data. Though initially it will focus on fistula treatment centres, the mapping exercise will be an ongoing information activity in the future, in order that it keeps all those in the field up-to-date about different activities and developments, and to facilitate communication between them.

Though mapping is important to the understanding of the extent of the problem, there is little doubt that obstetric fistulas, in Africa and Asia, still pose a major clinical problem (1–7). Access to modern obstetric care, including caesarean sections, can be limited in these countries. Therefore, a tremendous disparity exists between risks associated with pregnancy and labour faced by women in the developing world compared to women from wealthier nations (8,9). Over the course of a lifetime, 1 in 30,000 Scandinavian women will die in pregnancy or labour, whereas it is estimated that in some countries, such as Niger, up to 1 in 12 will die in Africa, particularly in the rural areas (10–16).

Furthermore, for every woman who dies in labour, it is estimated that at least another 20% of the remaining population may have to live with terrible injuries sustained during obstructed labour. Long distances combined with high cost of care and poor nutrition make women more vulnerable to obstetric fistulas, particularly in West Africa (11,17–19), the horn of Africa (20,21), the Middle East (22,23) and the Asian sub-continent (4,7,8,24–29).

3.2.1 Current status

It is estimated that there are up to 2 or 3 million cases of obstetric fistula still awaiting treatment (30). This is a conservative estimate, and is derived from national maternal mortality figures, using different statistical methods based on the national incidence of obstetric fistula and other epidemiological data (31–34).

The main treatment for all types of fistulas remains surgery which is carried out under meticulous circumstances. The success of the repair is dependent on good surgery, excellent nursing care and prevention of complications (35–38). Unfortunately, the number of capable and dedicated surgeons remains a major stumbling block in the management of these patients.

In Africa and Asia, initiatives were undertaken by doctors from differing surgical backgrounds, nurses and philanthropists to combat this debilitating problem. They all had a similar philosophy, to provide a dedicated centre of excellence to treat these patients. Thus, dedicated hospitals were established in many countries, including Ethiopia, Nigeria, Bangladesh and Sudan (38–42). All of these units not only treated patients, but also provided training and education, as well as raised awareness. However, several problems persisted.

Primarily, there was a lack of consensus on fistula classification (43), which affects the appropriate treatment of patients, prognostic evaluation and literature reporting. Secondly, most doctors worked in isolation with variable care practices, and thirdly there was little or no evidence-based medicine in decision-making. In addition, training in fistula surgery was often patchy, inadequate and unfocused. But most importantly, there was no way to assess trainees or determine their suitability. As a consequence, outcomes for some patients could be very poor indeed (44,45).

Other factors that are known to affect patient care include:

- *Health Systems:* Internal and external referral systems in every country, transportation systems, patient documentation issues and health systems are very different and can impact on the patient's journey to holistic care. Thus, each country has had to adapt to its local and regional needs taking into account specialized surgeon availability, cultural issues and logistic issues (e.g. religion, race, etc.). But it is transportation, in particular, that is a major problem in accessing both emergency obstetric care and fistula surgery, thus potentially restricting available health care.
- *Clinical Ability:* Recognition by the incumbent surgeon/doctor of their limitations and making decisions about complex/complicated cases which are not amenable to surgery. There are also other important issues, such as arranging long-term follow-up, understanding cultural sensitivities; promoting training and raising fistula awareness at a national level.
- *Fistula Tourism:* It is commonly known that doctors from around the world travel to different countries to carry out fistula surgery (46–48). But often, they can be ill-equipped to perform the surgery, do not remain long enough within the country to monitor the postoperative state of their patients and do not follow any guidelines or training strategies (47).
- *Early Fistula Management:* The lack of catheterization in the early treatment of vesicovaginal fistula, which is both safe and cost-effective, is a contributory factor to the persistence of a small vesicovaginal fistula (49). Though many surgeons advocate this approach, it has yet to be extensively used (50).

In addition to the clinical issues raised above, the politicization of fistula surgery in the developing world has also been a major difficulty for several decades, as government and non-government agencies struggle to control the “fistula market” (21,31,47). With increasing awareness of this condition (31), many agencies have poured money into initiatives of fistula care, but whereas in the past the health care providers were considered secondary to their projects, this appears to be slowly changing. However, global consensus remains the key.

But, the unmet needs of the fistula patient are not only about surgery. They also include the availability and training of specialist nurses, physiotherapists, counsellors, social workers, occupational therapists and rehabilitation specialists.

3.3 The Current Global Health Strategy in Achieving Change

For there to be global agreement, several impediments had to be overcome. Firstly, clinical efforts had to be coordinated in order to prevent duplication of care, as well-meaning charities were increasingly raising money for obstetric fistula projects, with replication of services in many countries. Communication channels needed to be opened to enable better coordination of efforts to ensure well-managed and targeted-service provision (51). This needed the input of all the fistula surgeons dedicated to working in the field to come together and form an organization. Such a body was created in September 2008 and is known as the International Society of Obstetric Fistula Surgeons (ISOFS). It includes over 120 members who work in Africa and Asia.

Secondly, there had to be a universal attempt to accept a fistula classification to enable accurate communication between units and surgeons about the conditions that they were treating. Although there are several systems in use, as well as published in the literature, only two have been validated (52,53). Unanimous agreement on a classification system would be a starting point. A consortium, established by the World Health Organization (WHO), United Nations Population Fund (UNFPA), International Federation of Gynaecology and Obstetrics (FIGO) and several non-governmental organizations and professional bodies along with ISOFS are trying to reach an agreement (32,54–56). Due to the paucity of evidence to support any such system, Johns Hopkins University and EngenderHealth proposed two prospective studies to try and meet this end. It is an extremely difficult area in the fistula arena on which to reach consensus, as it raises the hackles in many a surgeon. Once adopted, a classification system will be an invaluable tool for training, communication and multicentre research.

Thirdly, training in obstetric fistula surgery needs to be strengthened and supported. There are only a handful of units that are currently appropriately equipped to provide training to a satisfactory level, but the numbers are growing. They have experienced trainers, adequate number of cases and satisfactory training facilities. They are already equipping young surgeons with the necessary skills to return to the field to further extend this work. But, they can be hampered by independent bodies who have taken on the task of producing a “training manual” in an attempt to formalize the training process and to be “involved” in the fistula world. Training and education remains, to a large degree, disparate and imprecise, maybe because of a lack of expertise or direction (57). Understandably, a unified approach is desperately needed. The formation of the International Obstetric Fistula Working Group (IOFWG) and ISOFS has gone a long way in bringing together the many facets of training.

Yet these unmet needs should not touch upon medical training alone. In essence, one also needs to consider the availability and training of specialist nurses, physiotherapists, counsellors, social workers, occupational therapists and rehabilitation specialists.

3.3.1 Unifying education and training a new way forward

In the last few years, there have been two distinct unifying global initiatives – the formation of ISOFS and the recently completed FIGO-led competency-based fistula manual. This is with a view to standardize training and to provide a competency-based approach to fistula management and education.

3.4 The Challenge of Obstetric Fistula in the Developing World: The View of the Medical Professional Bodies

Obstetric fistula constitutes a major health problem in low-resource countries, with devastating effects on the lives of women and their families. FIGO took a lead amongst other clinical professional bodies in the field to direct fistula training and education. They are a global professional body, whose goals are to promote the health of women and their newborns, by improving the standards of practice in obstetrics and gynaecology. No more so is this needed than in the world of the fistula patient, and its acknowledgement of this problem is now recognized worldwide. In the last decade, its dedicated fistula committee has been working towards prevention and management of this disabling condition (58).

In tandem with the Royal College of Obstetricians and Gynaecologists (RCOG) in the United Kingdom, the committee of field-dedicated fistula surgeons devised and developed the competency-based training manual. To date, this is one of the committee's most important achievements, as its main aim was not only to help standardize training, but to properly equip the surgeons with the required technical skills to treat fistula.

The remit of the FIGO fistula committee was to reach a consensus on what a training manual should include, contribute to the classification debate, and develop an evidence-based course for a selected surgical or gynaecological trainee, who has attained at least three years of surgical training in their home country. The training structure is modular, with each module or subject area being further sub-categorized into specific objectives. Each module can be achieved within a stipulated period of time, as determined by the trainer and the trainee. But, rather than this as a process whereby trainees are spoon-fed, they are encouraged to follow a path of competency-based training, as provided by the RCOG. Using the agreed information provided by the fistula surgeons, they were able to formulate and develop learning tools, logbooks and performance-based assessments (PBAs) for each module. This is the first time such an initiative has been developed for a specific internationally recognized health problem. Using the manual will not only provide a guide to surgical training, but also initiate an audit of surgical outcomes, thus facilitating research in the field and promoting publication in the medical and nursing literature. In order for the manual to be fully accepted, a consensus on fistula classification must be reached. It is on this last awkward point that the success of the manual will rest, but perhaps with the help of ISOFS and the FIGO/UNFPA study groups, a consensus will be reached in time.

The role of ISOFS is increasingly important. Those surgeons, who are already working within a dedicated institution, are protected to some degree, but those who work in isolation will need local, national and international support. By agreeing to form a body of experts in the field, ISOFS has already overcome a huge barrier – acceptance of each other’s expertise and position.

From the urological point of view, the management of vesicovaginal fistula in the developing world should not only include the surgical treatment of the fistula, but also the care of its consequences on the lower and upper urinary tract function, in particular, the long-term management of complex urological reconstruction procedures (42,59,60).

Repairs of fistulas are determined by size, location, amount of scarring, degree of destruction of the continence mechanism, degree of ureteric injury and avulsion and pre-existing comorbidities (61). After complex fistula repair, two issues remain a problem – that of persistent incontinence in spite of an intact bladder (62–64), and of failure of repair (26,65–67). Regarding incontinence, Browning showed in a series of 318 women that it occurred in all of those with a complex fistula (64). The pathophysiological hypotheses are that it could be related to either an urethral sphincter injury during labour, soft tissue destruction of the intrinsic sphincter mechanism, permanent denervation or changes in bladder function (68). However, it appears this complication may be prevented or treated by slings such as fibromuscular or aponeurotic slings, or other complex surgical techniques (64,69–72). The training and education of surgeons undertaking these procedures need to be well structured and focused, and remains an unmet need.

Long-term surgery and management of urinary diversion procedures remains a major obstacle in the developing world, as the number of available urologists is limited and those that are present have to cover the whole gamut of urological surgery, including that for cancer (68,73–76). The complexities of complicated fistula surgery present many problems to the clinician (77). Continent diversions are not always accepted by the patients or their relatives, thus creating a dilemma for the patient, the urologist and the family. Moreover, specific devices or bags are needed to collect the urine and they are not always available to the patient and may be quite costly. Stoma support services are usually not available in many of these countries.

Urological societies like the Pan-African Urological Surgeons Association (PAUSA), the Société Internationale d’Urologie (SIU) and the International Continence Society (ICS) have started several initiatives to look into the post-repair issues in fistula surgery. SIU, in particular, has been involved in the education and training of urologists throughout the developing world and have established several centres such as that in Wad Medani in Sudan and Burkina Faso. By increasing the number of urologists, there will be an increase in the capacity of available fistula surgeons undertaking complex reconstructive surgery. Members of both societies are active members of ISOFS and the FIGO-led competency-based manual committee.

3.4.1 The future

Hitherto, the main focus in obstetric fistula has been in improving the capacity for treatment. However, prevention is the ultimate goal, and FIGO, the urological professional associations, in tandem with other non-governmental organizations such as the United Nations Population Fund and the WHO, address the improvement of maternal health services as a priority area through the implementation of projects in the field in low-resource countries, and strengthening the capacity of national associations to play a catalytic role in improving maternal and newborn health (54,78).

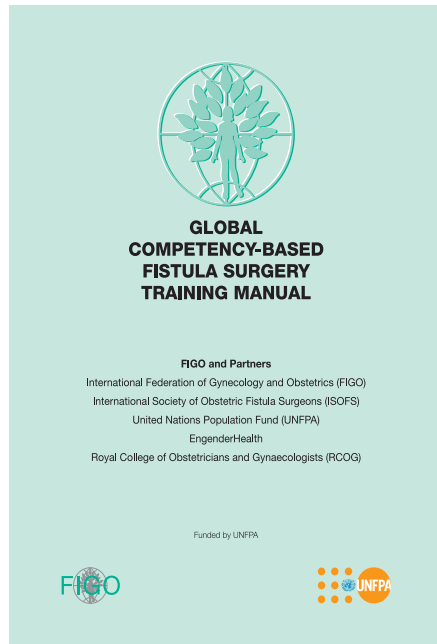
The challenge is great due to lack of resources, human and otherwise. However, the commitment of professionals has been the driving force in many countries, and their role should be encouraged and greatly supported.

3.5 FIGO and Partners' Competency-Based Fistula Training Manual

Many workers in the fistula field realized that the number of doctors who were well equipped with the necessary skills and knowledge to care for these women was scarce. Most of the surgery was being done by indigenous doctors living and working in Africa and Asia, but their numbers were few. Their main support was often from visiting doctors from the developed countries that were ill-trained to handle these cases. There is a huge need for training across the globe and specifically, training of doctors who are practising in the developing countries. It was realized that the current available numbers of trained professionals in fistula surgery would need years to treat the backlog without considering the newly emerging cases. There was no standard curriculum to train doctors in genital tract-fistula management and care. As a consequence of this issue, the initiative was taken up by FIGO, funded by UNFPA, to compile the competency-based fistula surgical training manual in 2008. This manual was produced with the collaboration of fistula surgeons, professional organizations and specialist health organizations from all over Africa, Asia, Europe and the United States of America. Without the personal dedication of all members of the committee, this manual would not have reached completion.

The purpose of this manual was to enable health care providers to acquire the required knowledge, skill and professionalism to prevent fistula and provide holistic care to fistula patients that included medical, psychosocial and surgical care. It is intended that the manual will be used by health care providers who are involved in the prevention and management of genital tract fistulas. A multi-disciplinary team-based approach is encouraged in the training of each doctor and his/her team of nurses, physiotherapists and other health professionals. The course is structured at three levels: standard, advanced and expert levels of fistula training.

FIGURE 1
FIGO: Global
Competency-Based
Fistula Surgery
Training Manual.



The manual is made up of several components:

- **Curriculum Modules**
Each module has an outline of the course content that the trainee is expected to be aware of. It needs to be used in conjunction with recommended references, and in some cases, with specific PBAs. There are seven modules that need to be undertaken.
- **Logbooks of Competency**
These are records of the work carried out by each trainee. Each must be signed off by each trainer, who will determine if the trainee has observed a procedure, has assisted with a procedure or is able to work independently. The trainer will determine if the trainee needs further training in a particular area. The logbook is comprehensive, and every section must be filled diligently and carefully (detailed outline below). There are seven logbooks that are to be completed, and they include a record of audits/protocols/processes that are to be undertaken throughout the competency assessments.
- **Performance Based Assessment (PBA)**
Each aspect of surgical training will be assessed separately and specifically. The trainees will complete each PBA to attain a standard-, advanced- and expert-level proficiency and ideally need the signature of two or more trainers, from two or more training centres (detailed outline below). It is expected that each trainee will undergo a prolonged period of fistula training at one or more centres. There are 15 PBA to be completed before a fistula surgeon can be deemed an expert, and will often require the full 24 months of training. However, this is a competency-based training manual and each trainee will require different lengths of time to achieve each level of expertise.

With regards to training itself, several requirements are considered essential by the FIGO and partners committee:

Training centres: Training centres will be determined by the Global Education Team, due to be set up by FIGO and ISOFS. Each centre must have adequate training facilities, as well as a reasonable throughput of fistula patients per annum.

Trainers: Each trainer would have undergone a “Train the Trainer” course run by the Global Education Team to ensure that they are familiar with and are happy to use the manual. Each trainee should be provided with the following information by the training centre and trainer:

- Name of principal trainer
- Name of hospital and number of beds
- Number of fistula repairs per year and outcomes
- Types and complexity of fistula cases
- Duration of training period available at the designated centre
- Physiotherapy, counselling and audit

In addition, a list of training centres and trainers will be provided to each trainee who applies for the training programme. This will be decided by FIGO and the ISOFS Global Education Team in tandem with other medical professional organizations.

Trainees: Most trainees will be trained within their country and its surrounding neighbours. When a candidate is selected for a particular unit, they will be given an overview of the hospital, as outlined above. Each trainee selected for this specialized training programme must assure the Global Education Team of their commitment and dedication to continuing long-term work in the field of fistula surgery, before commencing training. An outline of their training programme will also be prepared, and will include:

- Induction day at the hospital, to introduce candidate to staff and the hospital set-up
- Outpatient clinic to see patients, with trainer
- Demonstration of simple-/advanced-/expert-level of proficiency in fistula surgery by the trainer
- Assistance at surgery with the trainer
- Hands-on teaching of repair of fistulas at the simple, advanced and expert level

The expectation from each trainee has been laid out clearly in the manual, in the form of a course timetable and checklist. They are expected to attend different training activities, which will provide a diverse learning experience for them. Each activity is associated with a specific stage/level of surgical proficiency, categorized as standard, advanced or expert (**Table 1**).

TABLE 1 Recommended Tests for Staging at Diagnosis

| Learning session | Schedule | Checklist |
|---|--|-----------|
| Lectures | Standard stage of fistula training | |
| Skill laboratories (where available) | Standard stage of fistula training | |
| Group work with nurses, physiotherapists and counselors | Standard stage of fistula training | |
| Bedside teaching | Standard stage of fistula training | |
| Team discussions | Standard stage of fistula training | |
| Video learning sessions | Standard stage of fistula training | |
| Reflective learning sessions | Standard stage of fistula training | |
| Case-based discussions | Standard stage of fistula training | |
| Performing surgery | Standard/Advanced/Expert stage of fistula training | |
| Confidential diary entries and log-keeping | Standard/Advanced/Expert stage of fistula training | |
| Demonstration and participation | Advanced/Expert stage of fistula training | |
| Field visits to neighbouring obstetric units | Advanced/Expert stage of fistula training | |
| Surgical demonstration | Advanced/Expert stage of fistula training | |

Each country will determine how trainees will be selected for training. Currently the Ministry of Health, non-governmental health agencies and universities are selecting candidates for training. This is a highly individualized process in each country. However, final responsibility lies with the trainer. In addition to surgical training, all trainees will be taught how to perform audit, so they can use it during their training period and for future clinical practice. Trainees will also be expected to provide feedback on all their trainers and their training centres, to the Global Education Team.

Trainees who are selected to start training using this manual would be expected to be familiar with the subject matter and its published literature. Each trainee would be encouraged to read the recommended textbooks and relevant journal articles before commencing their training.

As this is a competency-based training manual, timelines are therefore not definitive. Thus, each training course will be determined by the trainee and the trainer. It is envisaged that each trainee will need at least three-months' experience in a dedicated centre to be competent in standard fistula management, 12 months in advanced fistula management and 24 months to become an expert.

This is in keeping with global guidelines in training specialist surgeons in dedicated fields of excellence, but by no means authoritative. These are simple time guidelines, and are therefore flexible and open to discussion between the trainee and trainer.

The trainee will be evaluated throughout the course using structured workplace-based assessments, group discussions (where available) and reports from the trainers. Checklists, assessments and logbooks are used to assess competence of the trainee. The logbook will be signed by the trainers and feedback on the performance of the trainees will be concomitantly given. The trainee would be expected to reinforce his/her performance by using recommended learning guides.

Each trainee will need to have the following assessments done:

Appraisal – A review of educational progression must be made after discussion with the trainers. These will take place on the first month after the commencement of training, and upon completion of each placement. Regular appraisals are very useful to ensure ongoing, structured development and regular communication. Appraisals identify problem areas early on and ensure trainees are satisfied with the education and support that they receive. These appraisals will need to be reported to the FIGO and ISOFS Global Education Team.

Reflective Learning – Learning to reflect on and from difficult clinical situations in which you have been directly involved is a vital part of being a good doctor. All must recognize that they should learn from a significant event by making notes or discussing situations after they occur. The trainees should reflect on their practice at all times, regardless of the interval of time, so they can learn from their mistakes and build confidence. It is important to write notes to clarify anxieties and to share ideas based on the points on the reflective learning form. Trainees should be encouraged to keep a personal diary.

Personal Development Planning (PDP) – PDP is a structured and supported process undertaken by an individual to reflect upon their own learning, performance and/or achievement and to plan for their personal, educational and career development. PDP embraces a range of approaches to learning that connect planning (an individual's goals and intentions for learning or achievement), doing (aligning actions to intentions), recording (thoughts, ideas, experiences, in order to understand and show the process and results of learning) and reflection (reviewing and evaluating experiences and the results of learning). When a trainee is assessed, PDPs should be completed for different aspects of their work.

Assessments – These include case-based discussions, logbooks of competence and performance-based assessments:

a. Case-based discussions (CbD)

This generic tool formalizes case discussion with the trainer. The curriculum indicates the competencies that can be tested using this tool. Trainees use the CbD to document objective assessments of discussion about cases. They can be used to assess clinical decision-making, as well as knowledge and application of that knowledge. Each case-based discussion should involve slightly different clinical situations in the competency area to be tested. The discussion will focus on the information given to the patient and recorded in the notes. These discussions need to be formally written up, but can take place in theatre, at the bedside or in the outpatient clinic with the trainer.

b. *Logbook of competency*

The logbook makes use of a simple system for recording the acquisition of clinical skills. Each module has specific training targets and the final level of competency is reached in stages, ranging from observation, through direct supervision, to independent practice.

c. *Performance-based assessments (PBA)*

There are a small number of procedures that are so fundamental to the practice of fistula surgery that an objective assessment tool has been developed to aid the assessment process. The PBA is a validated assessment tool to assess a trainee's technical competency in a particular technique. The curriculum indicates those skills that need to be assessed with PBA. The PBA should be used to help trainees and trainers to assess when they are ready to move on to independent practice for a procedure and when they are ready to be signed off for independent practice. The same PBA may be used to assess increasing levels of complexity for any particular procedure.

d. *Further aims of the assessment experience*

It is not possible to be prescriptive about the number of procedures that should be undertaken by each trainee, since rates of learning and clinical opportunities vary considerably. However, it is hoped that trainees will be able to demonstrate that they have been given increasing responsibility in carrying out the listed procedures over a period of 24 months, but based on competency assessment as determined by the trainer or trainers. The forms are designed to help to make this explicit.

Thus, the competency-based manual attempts to standardize and support surgical training in fistula repair. In the process of achieving this aim, it is envisaged that there will eventually be an increase in the number of training centres accredited and eventually surgeons trained.

3.6 Curriculum and Education Development in Fistula Surgery

To date there have been no general core curriculum developed for fistula training in the undergraduate or post-graduate medical education.

At the undergraduate level, theoretical knowledge, general principles of history-taking and clinical examination are the basis of early medical education. The core curricula are developed by individuals and/or medical institutions, but none of them are approved by professional organizations. Specific teaching on obstetric fistula, including formal assessment, should be provided to all young doctors training in countries, where obstetric fistula is prevalent. Indeed, some medical schools may choose to have a more detailed optional curriculum, similar to that devised by the FIGO-led group.

Post-graduate training in obstetrics and gynecology and in urology varies in different countries. Most curricula broadly include general anatomy, physiology and pathology of the bladder, pelvic organs and the rectum. Clinical history, examination, medical and surgical management, treatment outcomes and postoperative care pathways are all integral to the specialized training of these doctors. The main discussion here is whether all specialists training in countries, where obstetric fistulas prevail, should also be skilled in the management of fistulas.

In all curricula development, it is envisaged that knowledge of causation, prevention, surgery, rehabilitation and audit would be desirable.

In essence, it was these identified unmet needs that led to the development of the competency-based manual and curriculum for surgical training on obstetric fistulas. This manual can be used to develop a core curriculum in other aspects of medical training, at both the undergraduate and post-graduate level. It expects good theoretical knowledge, development of clinical skills, extensive sustained clinical practice and the use of audit tools (79). This can be achieved by access to devoted trainers, didactic teaching, course work, seminars and other educational techniques. It can be rolled out to eventually include training for specialist nurses, physiotherapists, rehabilitation therapists, community workers and patients (80–82). These are slightly separate issues, but they do contribute to the development of holistic care services for the fistula patient and her physician.

In brief, this singular need for effective and standardized training can be met by the competency-based training manual and its assessment processes. Awareness of this problem in countries where obstetric fistula is present must be raised in medical establishments (31,83,84). The authors believe that the curriculum, provided by the FIGO-led competency based manual, can be modified and be used as part of the future medical education of all undergraduates and post-graduates.

3.7 Fistula Training Models, Principles and Approaches

The strategy for fistula training recognizes and tries to address several distinct challenges that can hinder quality in training (85).

These challenges include:

- The many different clinical types of fistula and the widely divergent degrees of surgical complexity encountered both in repair and in training
- Lack of standardization in training, curricula and reference materials, duration and models for training and classification of fistula
- Standardization requires some collaboration with other key players and stakeholders, such as the International Fistula Working Group (IOFWG), FIGO, UNFPA, Engender-Health, WHO, PAUSA and others who can help develop a uniform training strategy. Standardization has begun, in the effort led by FIGO, but widespread roll-out and acceptance is still needed
- Differing approaches and skill sets for service provision and training
- Different training-site resources, including personnel, general surgical- and fistula-specific equipment, expandable supplies and training materials (library books, manuals, references, anatomic models, audio-visuals, videos/films, job aids, computer ware, case studies)
- Scarcity of evidence-based clinical research data (86)
- Lack of operational research data within different facilities

3.7.1 Key principles and premises in fistula training

The training approach is characterized by some key principles:

- **The welfare of the women** guides all training;
- A **combination of didactic and hands-on training is important**, both to bring less experienced surgeons to an acceptable baseline level of technical skill (for simple repairs (87,88) and to help bring surgeons with more experience to a greater level of technical skill;
- **Doctors and nurses are trained in teams** (along with counsellors or nursing assistants, if possible) whenever logistics allow;
- **Providers must consider and conduct training as an integral part of clinical care** (from pre-operative, intra-operative, through to postoperative periods) (89); and
- **Training should be competency-based and use adult learning principles:** final assessment of trainees will determine the level of surgical complexity or fistula class they are competent to repair. In essence, they need to be accredited to do each stage of fistula surgery. The accreditation and certification process will be determined by ISOFS and the international professional bodies.

Didactic sessions involve open and participatory learning activities. The facilitators meet regularly to review progress of the training and to plan subsequent activities. But training is also guided by experiential or reflective learning and by linking and evaluating it with performance (90).

3.7.2 Fistula training models

The strategy explores the use of different training models (modified from Bangser and the UNFPA fistula training workshop in Niamey, in 2005 [91]). The most frequently used models are (**Figure 2**):

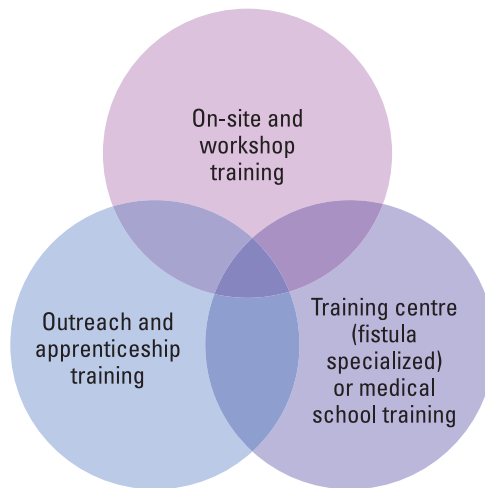
- *On-site training and workshop training*
 - Performed by a master trainer, who visits a hospital to do hands-on training
 - Intensive trainer-led training for a small group of surgeons at a busy centre
- *Outreach training and apprenticeship training*
 - A less experienced surgeon accompanies an expert surgeon during outreach visits to remote hospitals to gain exposure and training
 - A more experienced surgeon or mentor meets less experienced apprentice for periodic exchange and hands-on. This may be an on-the-job training, but needs to be structured and also use reference materials
- *Training centre (fistula-specialized) or medical school undergraduate- and post-graduate training (92)*
 - Establishment of a regular training program at a major hospital doing fistula repairs only (e.g. Addis Ababa Fistula Hospital or Katsina Fistula Services)
 - Teaching hospital structured hands-on training at a medical school setting or at an affiliated site, especially for residents in obstetrics and gynaecology, urology and surgery (e.g. Le Dantec University Hospital Senegal)

The different models often overlap. They may have varying strengths and relative weaknesses depending on local circumstances (e.g. implications of being trained away from one's own site for extended periods of time from sites that are commonly personnel-deprived already). The training strategy must be:

- robust, but have some degree of flexibility;
- adaptable to each country's needs and service requirements, but also fit in with the global educative model;
- modified to the training site's capability and its trainer's capacity for training, but ensuring complacency does not compromise the needs for training expansion.

Furthermore, even for a specific site and team, it may be necessary to change or to use a hybrid model to cater to update training, follow-up training and proficiency-level training. The model used in the long-term would presumably be determined after careful evaluation of each centre and its training capabilities, by its trainers and trainees (90).

FIGURE 2
Schematic representation of the most frequently used fistula training models



3.7.3 Community collaboration in fistula training

The role of the patient community and the fistula service is very relevant to improving training and education in this field (93–95). The community's representative can act as a liaison between fistula training sites and the community, thus identifying women or families in need, providing information regarding fistula-repair services and also spreading the fistula-prevention message (96–98). In addition, it can extend the fistula training site's capacity to track women following repair and support reintegration and link women and families with other sexual and reproductive health services.

Thus, it is quite clear that fistula training has to have different models of training for each level of health care provision, be it local, regional or national. What is applicable at one level, may not necessarily serve the purpose of the health care system at another level, and hence the model needs to be specifically adapted.

3.8 Summary and Recommendations

The evidence for training and education in fistula surgery is scanty and limited. In summary, three areas of importance need to be highlighted: raising awareness of the fistula problem, promoting prevention (31,96) and forging ahead with training and research.

Raising awareness of obstetric fistulas has been the reason why we are able to move forward, as a community, at this point in time (31,54). This exacting work has meant that more women are being treated, more dedicated units are being developed, more doctors are being trained and most importantly, more lives are being rebuilt. The WHO's mantra of "health security for women throughout the lifespan" is a platform for its future advocacy efforts to improve the quality of women's lives. No more so is this needed than in women suffering from a fistula.

Prevention can only be achieved by ensuring reproductive health rights for all women are available and accessible (96,99,100). This includes universal access to contraception (101), emergency obstetric services, improving medical care (including mental health care [102–104]) and instituting appropriately integrated social, economic and cultural development programmes (105–107). This would effectively prevent the problem. In the long-term, social and economic development will be more cost-effective than medical treatment, but more importantly, it will be highly sustainable. In the interim period, a holistic approach to medical and surgical treatment (108), rehabilitation and follow-up in the community would be the most appropriate.

In order that prevention is instituted and sustained, it is important that training in antenatal care, emergency obstetrics and pelvic surgery is improved so that obstetric fistulas become obsolete (109). Until then, training in fistula surgery needs to be actively supported and promoted. Current surgical training in fistula surgery includes apprenticeships and the use of training manuals. But there is scope for curriculum development and regular teaching at an undergraduate and post-graduate level. Research at the post-graduate level is essential, as there is a need to understand and improve on surgical outcomes (110), patient management and preventative strategies. Publication of such data, in tandem with multicentre work, would be encouraged.

3.8.1 Recommendations

Based on the evidence in the literature and the work currently in progress in the field of fistula management, our recommendations would be classified thus:

Grade A Recommendations

- Promotion and use of standardized competency-based training manual
- Professional training with certification/accreditation in partnership with ISOFS, FIGO, PAUSA, SIU and other professional bodies
- Access to training resources and to specialized trainers

Grade B Recommendations

- Flexible access to training centres
- Acceptance and strengthening of different training models

Grade C Recommendations

- Undergraduate and post-graduate teaching
- Support or membership of dedicated professional society

3.8.2 Future research

Though many papers and books have been written about obstetric fistula, the levels of evidence for much of the research remains at level 3–5, as many of the reports are based on personal case series. There is a great need for research in this area, and some of the suggestions by the group include:

Surgical outcome data:

- Facility-specific factors: catheterization policy, use of prophylactic antibiotics, type of anaesthesia
- Patient-specific factors: type/classification of fistula, size and character of fistula, etiology
- Recurrence of fistula: why? Is it because of failed counselling, limited access to hospital, or other factors?

Audit:

- Audit of use of different surgical techniques (111)
- Audit of use of the competency-based manual (trainees or trainers)
- Audit from fistula units or hospitals carrying out fistula surgery: number and complexity of cases (36,112)
- Publications from local centre and multicentre studies

Prevention and Social Reintegration:

- Role of caesarean section after fistula surgery: is it mandatory, what guidelines may we offer?
- Prevention factors: is it failure/lack of antenatal care services, is it cephalopelvic disproportion, is it lack of access to caesarean section, and is it lack of pelvic surgery training? (113)
- Social reintegration and rehabilitation: how easy is it for the patient to regain her position back in her community, has the patient gained access to work, does the patient have access to post-surgery physiotherapy and counselling, are the hospitals addressing cultural and religious issues?

3.9 Conclusion

It is quite clear that the unmet needs in obstetric fistula management are many. It is only by holistically tackling each aspect of the needs outlined above that they can be eventually met. In order to achieve this end, the fistula community needs to be unified, and training programmes need to be standardized so that outcomes improve (5,41,49,59,66,114,115). Prevention (3,28,35,94,113) and social reintegration must be focal points (9,11,35,80,105,106). Although all of these issues are important, the social and economic development of “at-risk” girls or women perhaps supersedes them (20,104,116–119). Without socioeconomic advances, many unmet needs may remain unmet. Thus in order to achieve the WHO aim of better health for all mothers, raising awareness (120,121), preventative strategies (96), training (57,91) and research (122) remain key factors in meeting the needs of obstetric fistula patients.

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Surgical Treatment of Obstetric Fistula

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agents of change
daughter
normal
dignity
accepted
education
empowered
new
smile
marriage
interaction
self
home
alive
life
happiness
laugh
joy
confident
fertile
husband
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4.1 Background

Obstetric fistulas remain a challenge for many developing countries. There is a direct relationship between the occurrence of obstetric fistula and the availability and quality of prenatal, perinatal and postnatal care. The fight against obstetric fistulas has many aspects of which surgical closure of the fistula is only one. Due to the extent of the problem worldwide, the general lack of funds, training facilities and local and national government support, it will be impossible to train the necessary number of fistula surgeons to provide Committee 4 with hospitals that can admit fistula patients, or to offer these surgeons a sustainable income based on their fistula work. Therefore, prevention by improving maternal health care is of utmost importance to eliminate this awful condition from developing countries.

4.2 Literature Searching Strategy

Recently the literature on obstetric fistula was reviewed by the ICUD (International Consultation on Urologic Diseases). This manuscript builds on the publication from 2009 (1). Mainly the articles published between 2007 and 2010 were analyzed and reported. From the standpoint of evidence-based medicine, the literature on fistulas remains disappointing. A total of 601 articles were identified using search engines such as PubMed and SUMSearch, of which 149 were published during the last three years. Out of this literature, only 17 surgical articles could be identified. Most of the published articles were observational studies. Currently, there are no evidence-based guidelines or well-designed randomized controlled trials. The major large-scale literature review is the last report from this committee (1). While there has been a gradual improvement in the number and quality of papers published on obstetric fistulas in the developing world over the last few years, none of these papers rises higher than level 3 evidence (2). There is still a generalized lack of reliable data on obstetric fistulas. For this consultation however, the committee made use of the large database and the monographs of Kees Waaldijk (3-6). Being able to integrate these data in this report, has allowed the committee to give a more balanced view of the current practices regarding the surgical treatment of obstetric fistula. Although these publications are not peer-reviewed, the abundance of data, the systematic data collection, its analysis, the number of patients and the absence of other data, justify the integration of these data in this report.

There is a clear need for more publications on obstetric fistula in the mainstream urological and gynecological journals. An effort will be made by the academic community to support the field workers of obstetric fistula in order to facilitate the peer-reviewed publication of their important clinical experience.

4.3 Introduction

Treating a woman with an obstetric fistula can be complex. An obstetric fistula can have a devastating impact on the social life of women and can come with significant comorbidities (**Table 1**). Restoring the integrity of the bladder and urethra will be the strongest predictor of successful social reintegration. However, closing the fistula will not always result in urinary (and/or fecal) continence. The persisting incontinence even after a successful closure of the fistula will be perceived by the patient, and those around her, as a failure. Restoring continence remains a challenge, especially in a fistula where the urethra and/or bladder neck have been destroyed.

One has to realize that the concepts of urethral closure and incontinence treatment were mainly developed by research in American or European postmenopausal women with stress incontinence and/or prolapse. Possibly these concepts cannot be extrapolated without further research to young premenopausal women with obstetric fistula. Women presenting with a complex obstetric fistula often have a substantial amount of peri-urethral, urethral, peri-vesical, vesical, cervical and peri-cervical tissue loss, which probably leads to different pelvic floor dynamics compared to postmenopausal women with stress incontinence and or prolapse where tissue weakness is the causal mechanism.

The role of the pubocervical fascia, the support of the urethra and the urethral sphincter complex must be understood, if one wants to engage in fistula surgery.

TABLE 1 The Obstetric Fistula Complex

| | |
|------------------------|----------------------------------|
| Musculoskeletal | Foot drop |
| Neurologic | Saddle block |
| Dermatologic | Ulceration, skin infection |
| Renal | Renal failure, hydronephrosis |
| Gynecologic | Amenorrhea, infertility |
| Systemic | Malnutrition, anemia |
| Social | Homelessness, divorce, isolation |
| Psychological | Depression, suicide |

4.3.1 Main continence factors

A significant postoperative problem facing obstetric fistula patients is urinary incontinence, despite successful closure of the fistula. To maintain continence, several anatomic structures need to function in a coordinated way:

- intact bladder neck/urethrovesical junction
- intact urethral anatomy
- static suspension by pubo-urethral ligaments, and the connective tissue connection between the anterior urethra/anterior urethrovesical junction/anterior bladder neck, behind the posterior symphysis, which gives dynamic support from the pubocervical (endopelvic) fascia, through its attachment to pelvic floor muscle, thereby securing and stabilizing the urethra in its anatomic position.

In this classic view a good support at the mid-urethral level and a good external urethral sphincter ensure continence in women. The urethral lumen is compressed by the anterior external urethral sphincter against the back support by the urethrovaginal fibrous tissue and its fixation to the pubic bone (pubo-urethral ligaments), and the tensor fascia levator ani (urethropelvic ligaments).

These classic views are challenged by recent publications. Delancey *et al.* showed that urethral pressure and not urethral support was most important in maintaining continence (7). The importance of the pubo-urethral ligaments is questioned by these authors. Morgan *et al.* showed that a smaller striated external sphincter (length-area index on ultrasound measurements) was associated with stress incontinence and poorer pelvic floor muscle function (8). It was also shown that there is no correlation between levator ani defects after childbirth and urethral pressure, stating that the mechanisms that lead to levator ani defects can spare the urethra (9).

Although the measurement of urethral pressures is not always reproducible, nor predictive for the occurrence of stress incontinence, these new insights show that our understanding of continence and incontinence mechanisms in women is still incomplete. Accepting that the major urethral closure mechanism is located in the mid-urethra, the preservation or restoration of this part of the urethra should be a critical factor in achieving postoperative continence. The anatomical length of the damaged urethra can give some indication.

The classification systems of both Waaldijk and Goh take this into consideration, although their cut-off points are somewhat different. Both classifications indicate that if the urethra is less than 1 or 1.5 cm long, then the risk of postoperative incontinence is higher. This implies that any healthy urethral tissue has to be preserved, no matter how little is left.

Another important structure is the pubocervical fascia (part of the endopelvic fascia). In the case of obstetric fistulas, this fascia will show defects. During dissection, however, it can easily be identified and it will hold strong sutures while restoring the integrity of this fascia. This vesicovaginal connective tissue normally supports the urethra and acts as a backboard to which the urethra is compressed to achieve continence. Recreating this backboard by re-approximating the damaged pubocervical fascia and resuspending it, is considered to be important in restoring continence (10).

4.4 Pre-operative Care

Pre-operative assessment not only includes the clinical assessment and preliminary classification of the fistula, but also the general assessment of the patient. Since many women with obstetric fistula are treated as outcasts by their environment, their health status might be impaired due to poor access to food and shelter, and limited aid from their family members.

Paying attention to the “hole” or the fistula alone is inadequate. Other aspects of the obstetric fistula complex must be assessed. Comorbidities are often found in obstetric fistula patients: these may involve one or more physiologic and anatomic systems sometimes referred to as “field injury” or obstetric fistula complex (e.g. musculoskeletal, neurologic, dermatologic, renal, and gynecologic). In addition, social and psychological issues (depression, divorce and malnutrition) need to be identified and taken into account when treating the woman. If these factors could interfere with the surgical treatment, appropriate care has to be offered pre-operatively. If not, these problems should be dealt with once the fistula is closed (11).

The clinical assessment of the fistula can be limited to the confirmation of the presence of a fistula at that moment. If the presence of a fistula is doubtful from the history or clinical vaginal examination, a dye test can be performed or, when available, a cystoscopy can be done. Ideally, a workup and classification of the obstetric fistula should be done pre-operatively however many feel that the formal classification of the fistula should be done under anesthesia when the patient is on the operation table just before surgery.

Despite limited resources in many facilities in developing countries, good surgical practice should include a basic pre-operative evaluation to address factors that may affect the patient’s intraoperative course and postoperative healing (e.g. anemia, infection including urinary tract and skin infections, intestinal parasites and malaria).

Some surgeons prescribe a drinking regime to their patients pre- and postoperatively to reduce the risk of peri-operative infections, to improve the bladder capacity, to reduce the incidence of clot formation due to hematuria and to evaluate the compliance of the patient with the peri-operative regime (5). Other authors do not adhere to this drinking regimen and seem to obtain similar results. There are no comparative studies available at this moment (12).

There are no good data in the literature on antibiotic prophylaxis for fistula repair. Some authors give no antibiotics, and use a forced-drinking regime to clear eventual urinary tract infection. Following international guidelines on antibiotic prophylaxis, one single prophylactic dose of a broad-spectrum antibiotic at induction of anesthesia before the surgery, could be recommended.

A recent randomized study compared either 80 mg gentamycin IV given immediately after spinal anesthesia with the extended use of amoxicillin, chloramphenicol or cotrimexazole postoperatively. The proportion of women with successful fistula closure was similar among the two groups; 94.5% (92.1, 96.9) for a single dose of gentamycin vs. 89.4% (86.2, 92.6) for an extended dose of other antibiotics. Length of hospital stay, the proportion of women with fever, the rate of post-repair infection, and the incidence of post-operation stress incontinence and other residual incontinences were not different among the two groups. This study suggests that a single shot of antibiotics at induction is effective (13).

4.5 Classification of Fistula

There is currently no single accepted system for classifying fistulas and a wide variety of different systems have been proposed. Classification of fistulas is important only if the classification can predict the outcome of the repair, particularly in terms of fistula closure and the chance of persistent incontinence after successful fistula closure. In recent fistula classifications, the size of the fistula and involvement of the urethral closing mechanism have been taken into account (6,14). Some systems attempt to classify fistulas according to the anticipated degree of difficulty of the repair, while others classify them according to the type of surgical intervention that will be needed (12). Systems based on the anatomical appearance of the fistula do not necessarily predict the difficulty of repair, nor the postoperative prognosis. Goh *et al.* recently reviewed the existing classification systems (15). The importance of classification was stressed at a WHO meeting in 2008 in Geneva. Consensus was reached on the fact that authors should adhere to the following principles and descriptions when reporting on obstetrical fistula, and state the:

1. Classification system used
2. Fistula location
3. Fistula size and dimensions (if the classification system used does not provide a detailed descriptive system)
4. Number of fistulas
5. Extent of vaginal scarring
6. Surgical approach and technique used
7. Functional aspects should be described, looking at urological, anal and sexual function
8. Healing of the fistula
9. Fistula closure rates (or anatomical healing)
10. Persisting incontinence rates despite a successful fistula closure (or functional healing) should be noted separately

The Waaldijk and the Goh classifications are the most frequently used fistula classifications currently (15).

4.5.1 The Waaldijk classification

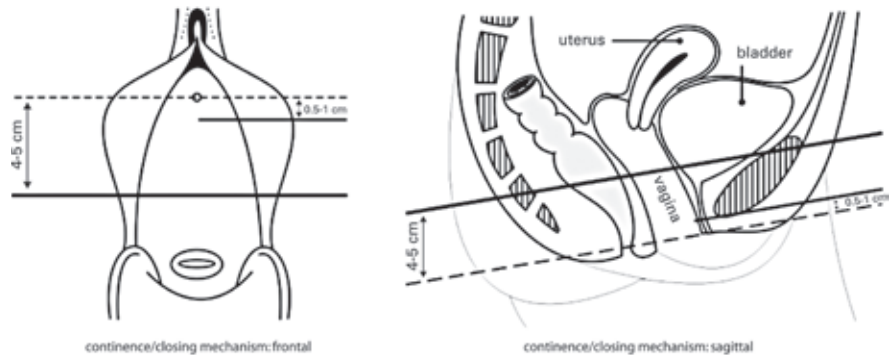
This classification system has been used for 25 years and large cohorts of patients have been studied. The classification system seems to correlate with outcome. Despite the large data set, there are no studies available on intra- and inter-observer variability.

The fistula is measured in centimetres (cm). The external urethral meatus is used as a reference point. The Waaldijk system uses three distinct categories:

- Type I fistula, not involving the urethra or bladder neck.
 - Type II fistula, involving the urethra. Type II is subdivided into:
 - IIA: preservation of the distal urethra (distal 1 cm, measured from the external urethral meatus)
 - IIB: there is loss of the distal urethra, so that the distance between the external urethral meatus and the distal fistula edge is < 1 cm
 - Type III fistula, includes less common fistula such as vesico-intestinal or vesico-cutaneous fistula.
- Both type II fistula classes are further sub-classified into:
 - a. not circumferential
 - b. denoting the circumferential nature of the defect
 - The size of the fistula, anal function, and anal sphincter anatomy are classified as well. Scarring of the vagina is not taken into account (16–17).

FIGURE 1A
Waaldijk classification diagram

© Kees Waaldijk



Classification of fistulas according to anatomic/physiologic location

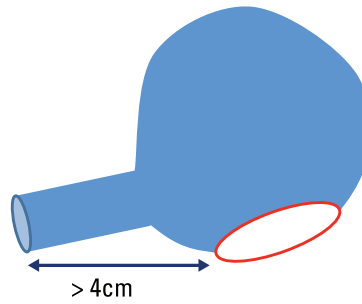
- I. Fistulas not involving the continence/closing mechanism
- II. Fistulas involving the continence/closing mechanism
 - A. without urethra or bladder neck involvement
 - a. without circumferential defect
 - b. with circumferential defect
 - B. with distal urethral (< 1 cm from meatus) involvement
 - a. without circumferential defect
 - b. with circumferential defect
- III. Miscellaneous, e.g. ureter fistulas and other exceptional fistulas

Additional classification of fistulas according to size

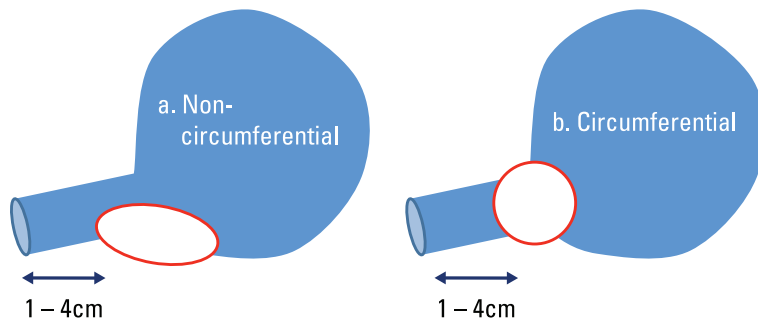
| small | medium | large | extensive |
|----------|--------|--------|-------------|
| < 2 cm | 2–3 cm | 4–5 cm | ≥ 6 cm |

FIGURE 1B
Schematic representation
of Waaldijk's classification
Type I and II

TYPE I : NO URETHRAL INVOLVEMENT



TYPE II A: PROXIMAL URETHRAL INVOLVEMENT



TYPE II B: DISTAL (&MID-) URETHRAL INVOLVEMENT

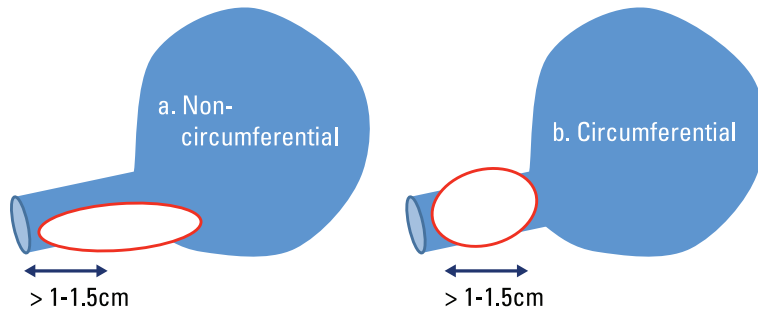
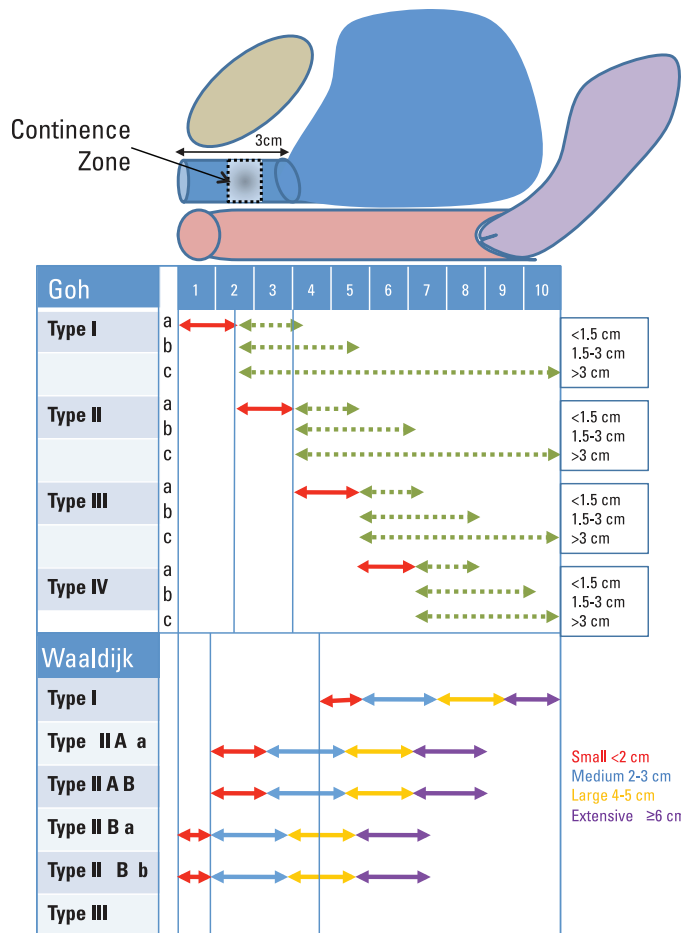


TABLE 2 Involvement of the continence mechanism in relation to the fistula classification

| Fistula Type | Involvement of Continence Mechanism | Continence Prognosis |
|--------------|--|---|
| Type I | No involvement | Good |
| Type II A a | Proximal mechanisms (bladder neck and proximal urethra): minimal involvement | Good |
| Type II A b | Circumferential destruction of proximal mechanisms: moderate involvement | Good if continence procedure is added to the fistula repair |
| Type II B a | Partial destruction of mid-urethral continence mechanisms: major involvement | Poor |
| Type II B b | Total destruction of mid-urethral continence mechanisms: extensive involvement | Very poor |
| Type III | No involvement | |

FIGURE 2
The Waaldijk and Goh Classification of Vesico-vaginal Fistula



4.5.2 The Goh classification

The classification of Goh also takes the external urethral meatus as a reference point from which the most distal edge of the fistula is measured in centimetres. There are four main categories, with three subcategories, depending on the fistula size. The amount of scarring is also noted (18). This classification has been used retrospectively to analyze failures after fistula repair. There are also limited data on intra- and inter-observer variability. The intra-observer variability was studied in 119 women. The three parameters (fistula type, size and scarring) all had Spearman coefficients between 0.82 and 0.87. The inter-observer variability was studied in 50 women, who were examined by two clinicians. Also in this study, the Spearman coefficients were high (0.84–0.86) with a Kappa of 0.74 (all $p < 0.01$) (19).

Figure 2 summarizes the Waaldijk and Goh classification. This figure illustrates that there is a potential overlap between several categories of both Waaldijk and Goh and that a conversion from one classification to another is not straightforward.

4.5.3 Classification systems and outcome

The predictive value of any classification system by itself is limited. Most authors agree that the functional and anatomical result will be less optimal with increasing size of the fistula, increasing amounts of scarring and increased urethral involvement (20). The experience and skill of the fistula surgeon and the quality of the postoperative care are both important for the outcome of the patient, but this is difficult to measure.

Goh *et al.* used the Goh classification to analyze retrospectively the occurrence of stress incontinence after a successful fistula repair (14). Women with fistula closest to the urethral meatus had the highest risk for postoperative stress incontinence. Also women with significant vaginal scarring and circumferential fistulas had a higher risk for incontinence and for failure of the closure. These factors however did not correlate with the fistula closure rate, but only with the post-closure stress incontinence.

Lewis *et al.* reviewed 505 cases in Sierra Leone (21). They used univariate and multivariate analysis to correlate classification and outcome. Univariate significant variables were: 1) the age at which the fistula occurred, 2) the index pregnancy, 3) the location and surface area of the fistula, 4) the urethral status and 5) the amount of fibrosis. In multivariate analysis, only the amount of fibrosis turned out to be significant in predicting outcome.

Nardos *et al.* performed a retrospective analysis of 1,045 patients of the Addis Ababa Hamlin Fistula Hospital (19). They found that a small bladder capacity, urethral destruction, circumferential involvement and severe vaginal scarring to be negative predictive factors.

On the other hand, Raassen *et al.* were unable to find predictive factors after multivariate analysis in a prospective study on 581 East African women (22). Only those women who were repaired within three months of the occurrence of the fistula had a better outcome (anatomical and social).

Waldijk prospectively followed 845 women after a fistula type II Aa repair and concluded that scarring and previous operations did not significantly influence the continence rate (10). He also evaluated 1,716 consecutive women, showing that the postoperative incontinence rate correlates with the urethral involvement.

TABLE 3 Results as to Fistula Type in 1,716 Consecutive Early Closure Patients (1992–2001)

| Type | Number | Healed First Attempt | Final Healing | Incontinent |
|------------|--------|----------------------|---------------|-------------|
| Type I | 243 | 238 (97.9%) | 242 (99.6%) | 1 (0.4%) |
| Type II Aa | 888 | 868 (97.4%) | 888 (100%) | 11 (1.2%) |
| Type II Ab | 366 | 333 (91.0%) | 353 (96.4%) | 30 (8.5%) |
| Type II Ba | 87 | 80 (96.4%) | 86 (98.9%) | 14 (16.3%) |
| Type II Bb | 132 | 114 (86.4%) | 121 (91.7%) | 59 (48.8%) |

4.5.4 Assessing bladder function

Patients with obstetric fistula sometimes leak for many years before they are offered help. During that time, the bladder capacity will reduce since the bladder never fills to completion anymore, because of the constant leakage. The eventual role of a reduced or increased fluid intake in this process is unclear. After surgery, the bladder capacity may normalize gradually, but if bladder compliance is already reduced by fibrotic changes in the bladder wall, this will not happen. Pre-operative assessment of bladder size can be done by palpation of the bladder wall through the fistula opening. Waldijk describes the measurement of the longitudinal bladder diameter (the length from urethral meatus to posterior bladder wall minus the length of the urethra). He describes four categories: ≤ 4 cm small, 5–6 cm moderate, 7–12 cm normal, > 12 cm increased (5). The relation of this classification with outcome is less clear, except for those in whom the bladder measurement is less than 6 cm.

4.6 Fistula Treatment

4.6.1 The early fistula

Little is known about the conservative treatment of vesicovaginal fistula. In most cases the diagnosis of a developing fistula is not made in the early days after a dystocic delivery or emergency caesarean section. Waldijk published his personal experience with the conservative approach to fresh obstetric fistula (4,23,24). He reported that of 2,031 patients (Kano + Katsina 1985–2008) who received immediate catheter treatment, 1,579 (78%) were cured completely; however, this group also included patients with “overflow incontinence” and total incontinence grade III; if catheter treatment failed, they were operated immediately once the fistula was clean.

So in total, out of the 4,424 patients who were managed immediately within 75 days postpartum, 1,579 (36%) were completely cured by catheter while 452 had early repair after failed catheter and 2,393 had early repair straight away.

A recent evidence-based review by Bazi on the spontaneous closure of vesico-vaginal fistula after bladder drainage alone came to the following conclusions (25). It was not possible to correlate the etiology of the fistula (obstetric or gynaecologic) with the likelihood of success. Most fistulas reported cured by catheter drainage alone are small, usually less than 1 cm in diameter. It was not possible to establish a relationship between fistula size and outcome, although a 5 mm diameter has been set as an arbitrary cut-off limit.

Duration of drainage utilized varies between 10 days and six weeks, but has not been studied properly. No data are available on which type of catheter drainage yields the best results. Fresh fistulas are more likely to close than those of longstanding duration. Although a real cut-off time has never been established, healing by catheter after six weeks to three months postpartum can no longer be expected since then there is an established fistula where the bladder mucosa has united with the vagina mucosa. If a fistula is diagnosed early, catheter treatment is certainly a good option, especially if there is no immediate access to a fistula surgeon.

FIGURE 3

Fistula of 3 weeks old.
Sloughing of the vaginal wall,
due to progressive necrosis
of vaginal wall, vesicovaginal
septum and bladder wall.



4.6.2 Surgical exposure and surgical approach

Fistula surgery requires some form of anesthesia. The position used during fistula surgery depends on the nature and location of the fistula to be repaired. For the vast majority of fistulas, a high lithotomy position with the buttocks pulled well over the edge of the operating table (steep head-down position), with or without episiotomies to provide enhanced exposure. Surgery in this position can safely be performed under spinal anaesthesia, which is the cheapest and easiest form of anesthesia for “low technology” settings in developing countries. Spinal anesthesia can be administered by the surgeon which is an advantage over general anesthesia (24). Vaginal surgery for small fistulas can be attempted under local anesthesia (26). Larger or more complex fistulas can be treated under spinal anesthesia, which is to be preferred over epidural or general anesthesia (27). Spinal anesthesia will yield better pain control than epidural anesthesia in rural settings (28).

Episiotomy

After positioning the patient on the table the surgeon must obtain adequate exposure of the operative field. For simple cases without scarring, the use of a weighted Auvard speculum should be sufficient. Sometimes a (bilateral) episiotomy is required to increase the exposure and to allow a weighted Auvard speculum to be inserted. When required, the episiotomy is usually done laterally (at 5 and/or 7 o'clock) which is extended as far as necessary to gain adequate exposure. After the fistula closure and the closure of the vaginal wall, the episiotomy or episiotomies are closed. Next to a formal episiotomy, any additional vaginal bands or strictures need to be severed to allow adequate exposure of the surgical field.

Vaginal versus abdominal

Experienced fistula surgeons may be able to repair most defects vaginally. Operating by the abdominal route increases surgical trauma, as well as the cost and time of the operation, but is still often performed for some high fistulas where vaginal access is problematic. If ureteral reimplantation is needed or if other concomitant procedures are necessary (e.g. colostomy) the abdominal approach may be preferred.

A retrospective study by Chigbu compared the outcome of juxta-cervical fistula from vaginal or abdominal approaches (29). Both approaches had similar cure rates and hospital stays, but the abdominal route was associated with a significantly higher need for blood transfusion. Moreover the study only compared juxta-cervical fistulas, which are relatively easy to access abdominally, whereas other types of fistulas are more difficult to access abdominally. General anaesthesia is also more expensive, more complicated to administer, carries more risks, and should therefore be reserved for those patients who need an abdominal approach.

4.6.3 Types of incisions

There are various types of incisions used to repair obstetric fistulas. The first operative technique was described in the first handbook on operative gynecology by the Dutch surgeon, Hendrick van Roonhuysen in 1663, who recommended the lithotomy position, good exposure by speculum, marginal denuding of the fistula edge and approximation of the fistula edge with sharpened stiff swan's quills; his principles are still valid. The great breakthrough came in 1852 when Marion Sims

utilized left-sided knee-elbow position, marginal denudation of fistula edge and one-layer closure of fistula with silver wire sutures (30). The techniques used to repair obstetrical fistulas have changed little since the pioneering reports by Simms over 100 years ago.

Obstetric fistulas come in different sizes and with the involvement of different anatomic structures. The incisions used to approach the fistula must serve different purposes:

- Providing a dissection plane that will allow adequate mobilization of the fistula tract and the surrounding bladder wall, allowing tension-free closure
- To ensure safe dissection planes; avoiding ureters, urethra, vascular structures, rectum, etc.
- To allow adequate closure of the vaginal wall once the fistula has been closed

Several types of surgical incisions have been described:

Simple circumcision of the fistula and Latzko's partial colpocleisis procedure

Latzko described his fistula procedure in 1942 (27–29). The incision circumcises the fistula tract and a plane between vaginal wall and bladder wall is developed. The fistula is then closed by approximating the denuded bladder wall in one or two layers over the fistula tract. The fistula tract is not excised and the vaginal epithelium is closed separately. This partial colpocleisis repair is suitable for small fistulas located at the vaginal apex (e.g. after hysterectomy).

J-shaped incision

The J-shaped incision circumcises the fistula tract and then extends the incision bilaterally in the shape of a “J”, with the fistula sitting in the curvature of the “J”. The J-shape can be directed anterior or posterior. By developing the vesicovaginal plane, two vaginal flaps are created. The shorter flap is excised to allow the larger flap to cover the fistula repair site, while avoiding superposition of both suture lines. This type of incision is also suitable for smaller fistulas without too much vaginal scarring.

Flap-splitting technique or Hamlin's technique

While it is impossible to describe in detail for every type of fistula that might be encountered, the following is a general description of the flap-splitting technique of fistula repair, as practiced by the Hamlins in Ethiopia, and used in the repair of nearly 10,000 fistulas. This technique was already developed by Collins in 1861 (31). This technique is currently employed by the majority of fistula surgeons around the world. In the original technique, wide mobilization was recommended, while nowadays many fistula surgeons limit their dissection to what is needed to allow a tension-free closure of the fistula.

The proximal margins of the fistula are incised and the incision is then extended laterally from the angles on either side. Using traction and counter-traction, the tissue planes are developed. The distal margins of the fistula are also incised. Two flaps are then developed, again using traction

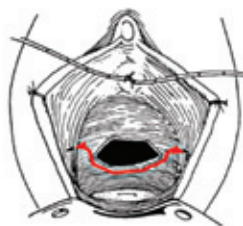
and counter-traction, and sutured away to the labia. Other surgeons prefer to make a less extensive dissection and limit their dissection to the point where they can close the fistula without tension. The fistula edges should now be fully exposed and mobilized.

The mobilization should be adequate to be able to bring the margins of the bladder defect together under no tension. Often the angles of the fistula are adherent to the inferior pubic ramus on either side. Releasing these attachments close to the bone gains much more mobility. This dissection can extend into the space of Retzius. It is also noted that the majority of the mobilization comes from the proximal dissection, not from the distal dissection and the amount of dissection reflects this. The distal dissection should really be only enough to secure a suture. It is best not to overdissect here as this merely creates scarring around the urethra.

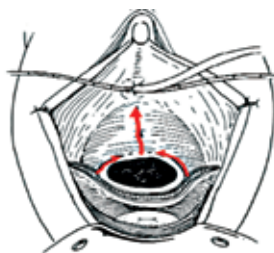
FIGURE 4B

Flap-splitting Technique

Identify ureters if needed and possible and catheterize them



Horizontal incision at fistula base



Anterior dissection as wide as needed



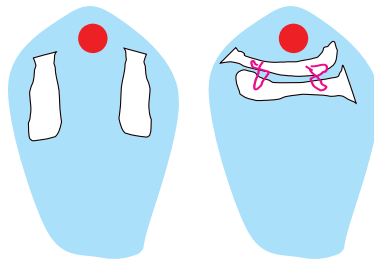
Tension-free closure
pubocervical fascia



Supporting stitches or
sling procedure

Most authors stress the role of the classification of the fistula in the selection of the surgical approach. By altering surgical technique according to the fistula classification, they try to prevent the high rate of postoperative incontinence. Waaldijk described his different surgical principles for the different types of fistula encountered (**Table 3**). Goh and Browning use their classification to recommend the use of a fibromuscular sling in patients with urethral involvement to reduce the incidence of postoperative stress incontinence.

FIGURE 5
Fibromuscular Sling
Procedure
SOLFA, used with permission



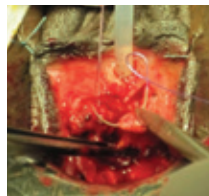
On both sides of the vagina fibromuscular tissue is harvested and brought together over the midline to act as a sling



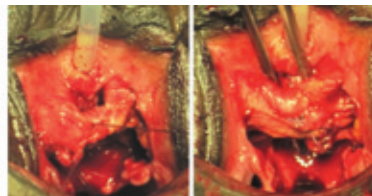
Urethra without support



Dissection of fibromuscular flap



Harvesting of fibromuscular flap



Forming a sling by bringing both fibromuscular flaps together over the midline

4.6.4 Surgical closure

In practiced hands, skilled fistula surgeons routinely achieve a closure rate of over 80% for simple fistulas at the time of first operation. Multiple papers reporting large case series support this contention (13,18,31–54).

In their large series of 2,484 obstetric fistula patients, Hilton and Ward reported successful fistula closure in 82.8% of patients at the first attempt (32). Successful closure was achieved in only 65% of those patients who required two or more operations. Another unpublished series of 400 patients from

the Addis Ababa Fistula Hospital reported a successful closure rate of 92% but persistent urethral incontinence of 33% at the first operation, a closure rate of 73% and urethral incontinence rate of 50% at the second operation and a closure rate of only 52% with urethral incontinence of 75% at the third operation (Browning, personal communication). Others have a different opinion and achieve higher closure and continence rates up to 95% in a mixed cohort independent of previous surgery, when the surgery is tailored to the individual fistula characteristics and to the individual patient, taking into account the involvement of the closing mechanism.

There is a tendency to report only about the first-operation attempts; this distorts the success rate because a considerable number of patients are left out. It is most important that it is not the success at the first attempt, but at the final attempt, since many women with fistula only achieve success after several attempts.

A fairly general consensus concerning the basic principles of fistula repair was reached at the first “Fistula Surgeons Experts Meeting” at the WHO in Geneva 2004. These principles can be summarized as follows:

- The best chance for successful fistula closure is at the first operation and closure rates tend to diminish with each subsequent attempt at operative repair.
- The ureters should be identified and protected to ensure they are not cut or ligated during the fistula repair (if the site and size of the fistula puts them in proximity to the operative field).
- The fistula should be mobilized from the surrounding tissues at the time of repair.
- The fistula should be closed without tension at the site of repair. Care must be taken to avoid bladder mucosa being caught in between sutures.
- The repair must be “water-tight”. To ensure this, a dye test is performed intra-operatively and if there is still leakage, the repair is sutured again. There is one very experienced fistula surgeon who does not do this, preferring to drain the bladder continuously for up to 4 weeks postoperatively.

Although these principles are valid and are practiced by most fistula surgeons, it remains difficult to establish good prognostic factors. The use of a classification system and the implementation of the correct surgical technique according to the type of fistula is certainly an advantage (Tables 3 and 4). Some prognostic factors, like urethral damage, will influence the continence outcome even when the fistula closure was successful. More research is needed to establish better prognostic factors.

Even more difficult to measure is the influence of the expertise of the fistula surgeon. Like in other surgical domains, high volume centres will probably achieve better results. The learning curve of fistula surgery has never been established.

TABLE 4 Operation Principles

| Type | Bladder/urethra Direction of Closure | Pubocervical Fascia | Anterior Vaginal Wall Closure |
|-----------|--|--------------------------------|-------------------------------|
| Type I | Any according to common sense | No special measures | Adaptation |
| Type IIaA | Transverse | Transverse repair (+ fixation) | Transverse adaptation |
| Type IIaB | Circumferential end-to-end | Refixation | Transverse adaptation |
| Type IIbA | Longitudinal (+ transverse urethra tissue) | Fixation | Flap |
| Type IIbB | Longitudinal + circumferential non-urethral tissue | Refixation | Flap |
| Type III | Irrelevant | Irrelevant | Irrelevant |

FIGURE 6

Resuspension of the Pubocervical Fascia in the Prevention of Stress Incontinence in Type IIaA Fistula. (Waaldijk 2008)



4.6.5 Protecting the closure and achieving continence

Supporting sutures

Any defect in the pubocervical fascia should be addressed, since this fascia is of importance in stabilizing and maintaining the mid-urethra, proximal urethra and bladder neck in its correct anatomical position (5). By restoring the pubocervical fascia and its bilateral attachment to the arcus tendineus fasciae pelvis, and thus the functional anatomy, a higher continence rate can be achieved (Waaldijk). However, identifying the arcus tendineus in a very scarred vagina might be difficult. In most cases a transverse defect exists, therefore the repair should be in the same direction.

In all patients, if possible, the remnants of this strong fascia need to be identified and repaired. In contrast to the field of prolapse in postmenopausal women, the collagen qualities of this fascia in young African women are stronger. Restoring this fascia will create a backboard against which the external urethral sphincter can contract and against which the urethra can be compressed during abdominal pressure rises.

Role of Martius flaps

There is debate as to whether or not a Martius bulbocavernosus flap or other flaps should be used in fistula repair. The argument has always been that such practices bring in a new blood supply to help nourish the injured tissues surrounding the fistula. One retrospective paper compared the surgical outcomes of operations involving similar fistulas repaired with and without the use of the Martius flap and demonstrated a higher successful closure rate when such a flap was employed (33). Another more recent retrospective analysis evaluated 400 patients in which comparable fistulas were repaired with and without the use of a flap. The analysis showed no differences between the two groups in closure rates or postoperative incontinence rates (34). Many experienced fistula surgeons now only use grafts under rare circumstances, such as when the urethra has to be reconstructed, when the tissues are particularly poor, or if there have been multiple previous attempts at repair. When the Martius flap is used as a sling, the flap does not add anything to achieving continence (Waldijk). Moreover the procedure adds a significant surgical trauma to the already existing obstetric trauma. One prospective randomized controlled trial compared the use of a Martius flap to the use of a self-made fibrin glue (57). There was no statistical difference in outcome, but the authors stated that the use of fibrin glue allowed the fistula repair to be quicker and simpler.

4.6.6 Anti-incontinence procedures

Preventing postoperative stress incontinence

Virtually all authors with extensive experience in the management of obstetric fistulas comment on the great difficulty in achieving postoperative continence in patients who have had extensive damage to the urethra, even if the defect itself has been closed successfully. Rates of postoperative urethral incontinence range between 6–50% (35) (59,60). Often the diagnosis of postoperative incontinence is given only if the patient suffers from severe incontinence while walking. If rigorous questioning is used to exclude any leakage with coughing or other exertion, the rate of postoperative incontinence increases dramatically. The type of postoperative incontinence is difficult to study. Stress urinary incontinence, urgency incontinence and overactive bladder (OAB), or mixed incontinence may be present (36). The differential diagnosis is difficult since urodynamics are not often available in developing countries. The use of validated questionnaires, translated into the local language, could be a significant step forward, but more research is needed.

The four risk factors that lead to a high rate of incontinence following fistula repair are: (61,62)

- **Urethral involvement** (odds ratio 8.4 for developing urethral incontinence postoperatively)
- **Large size of the fistula** (odds ratio 1.34 for each cm increase in size of the defect)
- **Severe vaginal scarring** (odds ratio 2.4 if the scarring is significant enough to prevent the introduction of a Sims speculum without relaxing episiotomies)
- **Small bladder size** (odds ratio 4.1 if the bladder capacity is less than 120 ml)

Surprisingly the presence of a circumferential defect doesn't seem to be a risk factor in this study, while other authors report it to be important. In a study on women with fistula, who had also undergone genital cutting, there was a slightly higher need to use a pubococcygeal sling at the time of the fistula repair (37).

In patients in whom all of the risk factors mentioned above are present, the postoperative incontinence rate may approach 100% (38). In light of this small success rate, some surgeons now suggest that two further principles of repair be maintained:

1. Maintain the urethral length

It has been noted that post-repair fistula patients returning for further treatment of persistent urinary incontinence often have a shortened urethra. An unpublished series of 72 patients with post-fistula repair incontinence found an average urethral length of 1.4 cm in these women (Browning, personal communication). This suggests that continence might be improved if normal urethral length can be maintained at the time of fistula closure.

Vertical (as opposed to horizontal) repair of urethrovaginal fistulas has therefore been suggested. This appears to be possible in approximately 20% of such cases. In cases in which there is an urethrovesicovaginal defect, vertical repair of the urethral defect may improve success by lengthening the restored urethra, while the vesical defect can be repaired either vertically or horizontally. However, the risk of subsequent urethral stricture and obstructive voiding has not been assessed in this study.

In Waaldijk's classification of pubocervical fascia defects, a transverse closure of this type of urethrovesicovaginal fistula would make more sense, since the normal anatomy is restored in a better way, provided that a suspension of the neo-bladder neck can be achieved.

2. Support the urethra

For all urethral defects larger than 4 mm with a urethral remnant less than 2.5 cm, many fistula surgeons use an "anti-incontinence" procedure during the initial repair. Currently there are two widely used procedures:

- The first procedure sutures the pubocervical fascia to the *arcus tendineus fasciae pelvis* in a type of suspension operation. The fascia or muscle of the bladder is sutured on either side of the bladder neck area to the posterior aspect of the symphysis pubis or the arcus tendineus (24) (**Figure 6**). With the use of these principles, the continence rate of any type of fistula is higher than 95%, with only 6.8% incontinence rate in 1,716 patients. In a prospective study of 845 patients with a Waaldijk-type IIAa fistula, out of whom 138 who had had 1–6 previous, the final healing rate was 99.4%, with an incontinence rate of the closed fistula of 2.6% (10).
- The second procedure creates a sling of tissue to support the urethra. A pedicle of tissue is created on either side of the urethra from the lateral pelvic side wall. In theory, this involves the use of the pubococcygeus muscle, but more often it is simply a pedicle of fibromuscular tissue or scar that can be harvested. The pedicles created on either side are then sutured together in the midline. (**Figure 7**). If this extra step is used, the incontinence rate after closure of complex fistulas can be reduced from 100% to 50% (38).

Treating postoperative stress incontinence

The overall incidence of post-repair stress incontinence varies between 6.7%, 14.2%, 17%, and 23.8% (14,15,64,65). Goh and Waaldijk both showed that the risk correlates with the fistula classification (6,18). In the study by Rijken *et al.*, the stress incontinence rate decreased spontaneously from 16.2% to 6.2% after 6 months (39). Although there may be spontaneous improvement in continence – with or without pelvic floor exercises – these data must be interpreted with care since 41% of the patients were lost to follow-up. The committee recommends that postoperative stress incontinence should not be treated invasively before six months.

Several surgical methods have been described for treating fistula patients with post-closure stress incontinence, including a sling or graft made of labial fat incorporating the bulbocavernosus muscle, remnants of the pubococcygeus muscle, a gracilis muscle flap, as well as fascial grafting (33,67). A Burch retropubic bladder neck suspension may work in a few patients (24), but in general the results of this approach have been disappointing. Carey and co-workers reported a small series of patients who had undergone previous fistula closure and who later underwent re-operation for stress incontinence. After urodynamic testing, nine women with severe genuine stress incontinence underwent a retropubic urethrolysis and pubovaginal sling procedure combined with placement of an omental J-flap. Four weeks after surgery, 78% were continent; however, this fell to 67% at 14 months follow-up (40).

An operation described by Waaldijk involves urethralization of the bladder neck: a longitudinal raphy or repair of the pubocervical fascia is performed, while the “vesicalized” portion of the proximal or mid-urethra or the bladder neck is supported again and shaped into a urethra. Following this, a fascio-colposuspension to the arcus tendineus is performed. Cure rates of 60–70% have been reported, but these results have not been replicated in other fistula centres and long-term follow-up is lacking (24). It may be that the fistula patients respond better to this treatment because of their young age and because of the pathophysiological differences between a postmenopausal woman with weakened tissues and a young fistula patient with strong, but partially destroyed tissue. On the other hand, organizing long-term follow-up in fistula patients is challenging, limiting the availability of good data.

The operation described by Browning involves urethralization of the bladder neck and creation of a “suspensory sling” from pubococcygeus muscle or fibrous tissue remnants along the pelvic sidewall. In a small series, 8 of 12 patients (67%) were completely cured in the short term (41), which is similar to the results of the post-fistula repair operation for urinary incontinence, described by Waaldijk (42). The results obtained with this relatively simple, low-cost operative procedure have not been replicated in other centres, nor are there long-term data on outcomes.

An alternative approach for those patients who fail a surgical procedure or who are deemed unsuitable for an attempt at surgical repair is to use a urethral plug (43). Although successful use of urethral plugs and various injectable materials has been reported, these technologies are not usually available in areas where obstetric fistulas are common. However, if an ongoing supply chain can be arranged, urethral plugs seem to work well for many women, with a high degree of patient satisfaction.

Overactive bladder symptoms can often be treated with low-cost antimuscarinic drugs. In cases where there has been extensive loss of bladder tissue or marked reduction in bladder compliance due to fibrosis, augmentation cystoplasty can be performed, usually by interposing a segment of bowel. In some cases, urinary diversion may be indicated, but only after careful discussion of the issues involved with the patient.

Ascher-Walsh *et al.* studied the use of polypropylene sling procedures after the repair of obstetric fistulas in Niger. They studied 140 women with persisting incontinence after a successful fistula repair, of which 127 were available for follow-up after two months. Their results show that women who undergo sling surgery – although with different types of slings and small patient numbers – after a fistula repair have a lower success rate than Western women who get a sling for stress incontinence (Table 5). The high prevalence of detrusor overactivity, sphincter tissue loss and decreased bladder capacity are probable reasons for this difference (44). Tafesse *et al.* did a cross-sectional study of patients who underwent a retropubic urethrolisis and subsequent sling operation (45). They reported a 41% success rate and 8.9% retention, with a high complication rate of more than 30%.

TABLE 5 Ascher-Walsh Results

| Technique | N | % Dry | % Retention | OAB | De Novo Fistula | Persisting SUI |
|---------------------|----|-------|-------------|-------|-----------------|----------------|
| Fascia lata sling | 96 | 25% | 4% | 16% | 18.7% | 35.4% |
| Rectus fascia sling | 16 | 12.5% | 6% | 18.7% | 12.5% | 50% |
| Synthetic sling | 15 | 33% | 7% | 0% | 13.3% | 26.7% |

Urethral reconstruction

Several types of urethral reconstruction have been described in the mainstream urology and pediatric urology literature. Some of those principles may apply to urethral reconstruction in fistula patients (38,55,59,72–84). However, in most cases, this may not be possible due to a lack of adequate healthy tissue. Alternatives may be to harvest tissue from the lateral vagina wall or sometimes by to advance bladder wall tissue. The most difficult, however, is to achieve continence and normal bladder emptying afterwards. Waaldijk recommends that the reconstructed urethra should always be fixed to the underlying pubocervical fascia.

Often, destruction to the vagina has been so extensive that rotational flaps are required in order to cover the defect (46).

Though in vaginal fistula repair, part of the bladder can be left uncovered (if there is no anterior vagina wall left or if it is totally fixed), the urethra must always be covered either by advancement or rotation flaps or by suturing the labia over it.

4.7 Postoperative

As with every surgery, in the immediate postoperative period, vital signs should be checked regularly to detect fluid imbalances, bleeding or anesthetic complications. As soon as the patient is able to get out of bed, ambulation should be encouraged.

4.7.1 Catheter drainage

After fistula repair the bladder should be kept on free drainage for 10–14 days. There is some weak evidence that 10 days of drainage is just as effective as longer drainage, assessed at six months follow-up (for fistulas of less than 3 cm diameter with mild to moderate scarring) (47). This change in catheter management could make a significant impact on the resources of hospitals where these operations are performed. If the time needed for postoperative bladder drainage could be reduced by four days, the capacity of the hospital to care for fistula patients would increase by 30%, just from this gain in efficiency. This argument, however, is not applicable to all fistula hospitals, since the setting and the use of patient hostels, rather than hospital beds, can alter the need for bed capacity considerably. Also, not all fistulas are less than 3 cm and others involve the urethra or are circumferential and the vagina is scarred. In all these cases, the surgeon might want the catheter to stay in at least 14 days or more. So the actual capacity would only increase perhaps by 15 or 20%.

Each day, the “3–Ds” of postoperative fistula repair are checked. These are whether the patient is Dry, Drinking enough and the catheter is Draining. The patient must be dry; that is, the fistula repair must be intact; drinking to ensure adequate irrigation of the bladder; and draining, that is, the catheter is not blocked. If the catheter does become blocked and the bladder fills, the repair is at risk of breaking from increasing tension on the repair site. If the catheter does become blocked and the repair ruptures, this may often be rectified by continuous prolonged catheter drainage. By ensuring an empty and relaxed bladder, the sides of the defect often come together and close, but this can take as long as 4–6 weeks to occur. The success rate is about 70% in such cases, less if the defect involves the urethra.

4.7.2 Infection

Postoperative infections need to be diagnosed adequately. The differential diagnosis of postoperative fever is not easy. First, malaria needs to be excluded (or treated empirically), as well as pneumonia. The operative site needs to be inspected. If there is abscess formation, this should be drained adequately. Waaldijk is the only author reporting on postoperative mortality. According to his data, infectious events (wound infection, malaria, sepsis, gastroenteritis) do occur in the immediate postoperative period, but can be consequences of native medicine, stroke, thromboembolism, etc. and may explain his 2% mortality. In recent years the mortality was reduced to 0.4%. Even eclamptic fits may occur and cause death in patients who have a history of eclampsia. They should receive magnesium sulfate or diazepam on the operative day to prevent this (Waaldijk, personal communication).

4.7.3 Bladder training and pelvic floor rehabilitation

Postoperatively, the bladder and urethra undergo changes. The bladder that has not been filled for a variable amount of time suddenly has to comply again with regular bladder filling and emptying. Also, the urethral sphincter will have undergone some degree of disuse atrophy. After the fistula repair, the recovery of these functions can take a variable amount of time.

It is unclear from the literature whether bladder training and pelvic floor therapy can improve these functions or shorten the recovery time, although personal experience of some authors indicates positive effects. Some promote bladder training by drinking classes and give basic information about pelvic floor muscle exercises. There is a need for prospective data.

4.8 Rectovaginal Fistula (RVF)

Rectovaginal fistulas appear to be less common than vesicovaginal fistulas in developing countries. In one (unpublished) series of 75 obstetric fistula cases from Ethiopia, only 6.7% were isolated obstetric rectovaginal fistulas and 84% were associated with significant vaginal scarring. Two of the 75 required a temporary diverting colostomy prior to repair; both were high fistulas adherent to the sacral promontory. This compares to 15% needing a diverting colostomy prior to RVF repair in Addis Ababa (Kelly, Kwast 1993). Waaldijk reports on the number of RVF repairs he personally operated between 1984 and 2008. Of the 18,563 patients he operated 12% had an RVF. In his larger database throughout other Nigerian fistula centres that he supervised, 2,587 patients out of 29,684 underwent surgery for RVF (8.7%) (6). He reports an 85% success rate.

Classification of RVF

In the abdominal surgery literature few classification systems have been described.

Fry *et al.* classified the fistula as 1) high (close to the cervix), 2) low (near the dentate line) and 3) middle (in between high and low) (48).

Rosenhein *et al.* proposed a classification of five types based on anatomic differences and the functional importance of the perineal body (49) (**Table 6**).

TABLE 6 Rosenhein's Classification System for Rectovaginal Fistula

| Fistula Classification | Description |
|------------------------|--|
| Type I | Loss of perineal body without identifiable fistula |
| Type II | Loss of perineal body with a fistulous tract involving the lower third of the vagina |
| Type III | Fistulas of the lower third of the vagina with an intact or attenuated perineal body |
| Type IV | Fistulas involving the middle third of the vagina |
| Type V | Fistulas involving the upper third of the vagina |

Waldijk also reported a classification system for rectovaginal fistula, which follows the same principles as his classification for vesicovaginal fistula, taking into account the eventual damage to the closing system and the size of the fistula (**Table 7**).

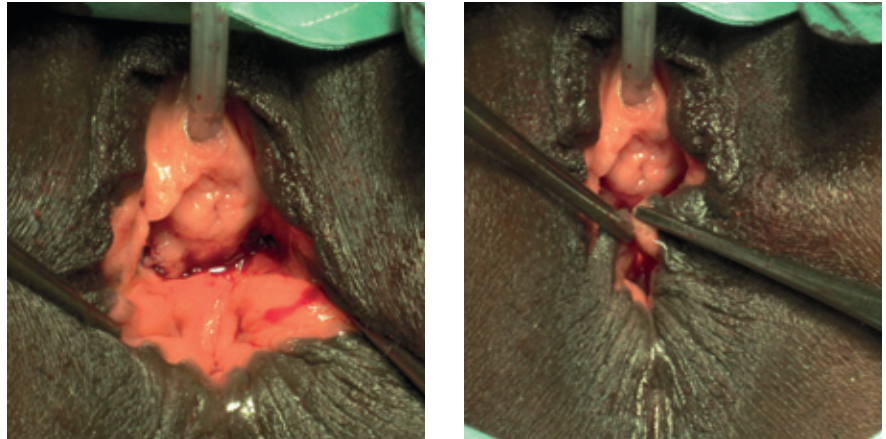
For the reference line, he uses a demarcation line 4–5cm from the vaginal posterior wall, to distinguish between fistula involving the anal continence mechanism, and those which do not affect this. Another important factor is the eventual (common) presence of a rectal stricture close to the site of the fistula, which needs to be taken into account during the repair.

TABLE 7 Waldijk Classification System for Rectovaginal Fistula

| |
|---|
| I. Proximal fistulas not involving the continence/closing mechanism |
| a. without rectum stricture |
| b. with rectum stricture (common) |
| c. with circumferential defect (not common) |
| II. Distal fistulas involving the continence/closing mechanism |
| a. without sphincter ani involvement |
| b. with sphincter ani involvement |
| III. Miscellaneous, e.g. ileo-uterine fistulas after instrumental abortion |
| Additional classification of fistulas according to size: |
| ▪ Small: < 2 cm |
| ▪ Medium: 2–3 cm |
| ▪ Large: 4–5 cm |
| ▪ Extensive: ≥ 6 cm |

FIGURE 7

Type II b anal fistula.
Perineal body is destroyed
and external sphincter is split.



Rectovaginal fistula repair

The basic principles of vesicovaginal fistula repair also apply to the repair of rectovaginal fistulas: mobilization of the fistula and a tension-free closure (48,60,87,89–92). The vaginal epithelium is incised around the circumference of the fistula and laterally from either angle. The vagina is reflected away and the bowel is mobilized, paying special attention to the release of any lateral attachments. Severe bleeding can occur along the lateral aspect of the bowel. The bowel muscularis is repaired in two layers, preferably in a horizontal plane to avoid creating strictures within the bowel lumen. The vagina is then repaired.

Waldijk bases his surgical approach on the classification of the fistula. These are summarized in **Table 8**.

TABLE 8 Surgical Approach to the Repair of Rectovaginal Fistula (RVF) Based on Waldijk's RVF Classification

| Fistula Classification | Surgical Approach |
|------------------------|--|
| Type Ia | Transverse closure of rectum |
| Type Ib | With disruption of rectum stricture |
| Type Ic | End-to-end anastomosis (after disruption of strictures); exceptionally combined abdomino-vaginal approach with colostomy |
| Type IIa | Longitudinal closure of anorectum |
| Type IIb | Meticulous reconstruction of all the structures involved |
| Type III | Depending upon the situation |

This classification, however, has no relationship to the surgical outcome. Only type Ic is considered to be difficult and to have a high complication rate. Only this type may need a temporary colostomy, according to Waaldijk (6).

Tafesse proposed a classification that takes into account the degree of rectal involvement, the tissue loss of the posterior vaginal wall, the accessibility of the proximal edge, the involvement of the anal sphincter and whether it is a primary or secondary repair (50). There are so far no published data on the usefulness of this classification.

Colostomy is normally not required in RVF repair. If in selected cases a colostomy is required, one must make sure that the repair is performed 2–3 weeks after the colostomy and that the colostomy is closed 4–5 weeks after successful RVF repair. Colostomy on its own is not a definitive solution for an RVF in an African context, where colostomy appliances are usually not available. More research is needed rectovaginal fistula.

4.9 Quality of Life

Quality of life (QOL) is poorly studied. There are some data on mental health showing that depression is more prevalent in fistula patients. In addition, it has been shown that mental health is positively influenced by a successful treatment of the fistula (51). There is a need to introduce standard questionnaires on QOL by translating them and validating them in the local languages. Since cell phones are now available in many African countries, the possibility of doing telephone follow-up interviews could be explored.

4.10 Pregnancy Post-Fistula Repair

The effect of fistula repair on subsequent pregnancy has been studied in Ethiopia (52). They followed a group of 49 women who had undergone fistula repair. There were three pregnancies within the group following the fistula repair and prior to the supervised deliveries in question. One ended in a miscarriage; one delivered on the road on her way to a hospital and had a stillbirth after 18 hours of labour; one delivered by assisted vaginal delivery in another hospital, presenting after two days of labour, had a repeat of her fistula and a stillbirth. The average time from fistula repair to delivery was 37.5 months (range 7–288 months).

Five patients had a planned elective caesarean as they were quite certain of their period dates. All of these had a live child. Forty-one patients had an emergency caesarean; two were performed following premature rupture of membranes (PROM) and the remainder at the onset of labour. One patient had twins (both were born alive) and one patient had a stillbirth. The fetus was alive at the onset of labour, but there was a delay in instituting the caesarean delivery within the government hospital by six hours and the child was stillborn, with the umbilical cord wrapped three times around the child's neck.

There were three vaginal deliveries; one was a precipitous labour, delivering a live child within 30 minutes of the onset of labour. The second was a mother at 26 weeks' gestation with severe malaria and premature delivery. The neonate died within 30 minutes of delivery; the mother fully recovered. The third was a spontaneous delivery at approximately 30 weeks' gestation. The neonate died within one hour of delivery. There were no recurrences of the obstetric fistula in any of the reported deliveries.

Thus, from 49 deliveries, there were 50 neonates (one set of twins) with the loss of three; two from prematurity and one from delayed institution of a caesarean section.

The optimal way of managing labour following obstetric fistula repair is to provide a waiting area for women as they approach term and perform a timely caesarean section. This should be at around term, in those women whose due dates are known with some confidence, or otherwise at the onset of labour.

4.11 Irreparable Fistula

Not all fistulas can be repaired at the first attempt. Some require more than one operation. Despite this, some fistulas cannot be closed to satisfaction. While everybody accepts that these patients exist, it was unclear on which criteria to base the decision to consider a patient being inoperable (53,54). The decision should be made by the most experienced surgeon available at the centre. Some patients who cannot be operated vaginally can still be helped by a urinary diversion. The decision to offer a urinary diversion (Bricker diversion or uretero-sigmoidostomy) has ethical and practical consequences that should be discussed in detail with the patient and her family before the surgery. Although the evaluation might be subjective and surgeon-dependent, the following factors were considered by the committee to be relevant in the decision-making process:

Patient-related factors

- Patients with a permanent poor general condition, in whom an extensive operation would be life-endangering

Fistula factors

- Most are extensive; Waaldijk type IIBb
- Extensive tissue loss of the anterior and lateral vaginal walls with extensive damage to pelvic floor musculature, with large bladder defect and exposed ureters retracted in the upper part of the vagina (eventual indication for diversion)
- Extensive urethral loss
- Extreme scarring
- Fixed bladder not allowing any mobilization
- Dissection carrying risk of major bleeding or additional urethral trauma

Incurable incontinence

- Small bladder capacity
- Loss of bladder compliance due to fibrosis
- Inability to create adequate urethral support due to extensive scarring

In these patients, the therapeutic options are limited. Conservative management is of course a possibility. In selected women, a urinary diversion might be considered. Uretero-sigmoidostomies can be used, taking into account that there is an eventual risk for the development of carcinomas at the uretero-sigmoidal anastomosis. Ileal conduits can be used if stoma bags can be provided. The experience with continent diversions is limited.

4.12 Recommendations

4.12.1 Assessment

Early detection of fistulas could improve by examining all women after their delivery or caesarean section, who suffered prolonged labour and are at risk of developing an obstetric fistula.

Associated pathologies should be actively searched for and taken into account in the treatment plan; all components of the “obstructed labour injury complex” should be examined.

Classification of fistula is recommended. Although many classification systems exist, the committee recommends the use of the Waaldijk classification, since it is supported by the largest amount of data (Level of Evidence 3).

The formal classification of the fistula should be done under anesthesia when the patient is on the operation table, just before surgery.

4.12.2 Treatment

Immediate management of the fistula by catheter and/or early closure will prevent the women from becoming outcasts (Level of Evidence 3).

A vaginal approach under spinal anesthesia is preferred.

A tension-free single layer closure of the bladder wall and closure of the vaginal wall in a separate layer are advocated. A Martius flap in primary obstetric fistula repair is not recommended.

In principle, most fistulas can be dealt with by vaginal approach, but an abdominal approach can be useful in some cases (e.g. concomitant reconstructive procedures). Advanced training and surgical skills are prerequisites for treating this type of fistula.

When reporting on outcome after fistula repair, authors should make a clear distinction between fistula closure rates and postoperative stress incontinence rates, and the time at which the follow-up was organized.

Prevention of postoperative stress incontinence must be added to the surgical procedure if the urethral closing mechanism is involved. This can be done by a good repair of the pubocervical fascia and refixation, or by adding a sling procedure (Level of Evidence 3).

4.12.3 After care

Surgical treatment of postoperative stress incontinence should only be considered six months after the fistula repair. There is no place for synthetic sling material in that setting.

A care program for failed repairs and for persisting incontinence after a successful repair needs to be installed.

A waiting home should be provided for women who become pregnant after a fistula repair to ensure that an elective caesarean section can be executed (Level of Evidence 3).

4.13 Research Priorities

4.13.1 Assessment

Concerning the classification of fistula, there is a need for more data on intra-/inter-observer variability of the existing systems.

The relationship between the classification and the surgical outcome of the fistula repair needs to be studied prospectively and preferably in a randomized-controlled way.

Techniques of quality of life assessment should be studied. Translation and validation in the local context of existing international questionnaires should be done.

4.13.2 Treatment

The optimal duration of indwelling catheterization in the treatment of early fistulas and in operated fistulas should be studied.

Comparative randomized studies are needed regarding the best techniques for the prevention of postoperative stress incontinence.

Studies are needed on the potential role of pelvic floor rehabilitation techniques in the treatment of postoperative stress incontinence.

4.13.3 After care

Long-term data and follow-up, especially towards fertility and subsequent pregnancies, and their outcomes are needed.

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C5

Complications of Fistula Repair Surgery

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5.1 Introduction

In the developing world, the true incidence of obstetric fistulas is unknown, as many patients with this condition suffer in silence and isolation. Obstetric fistulas destroy the lives of many young women in the developing countries. Some estimates place the worldwide prevalence as high as 2 million women worldwide. In some rural areas of Africa, the fistula rate may approach 5–10 per 1,000 deliveries, which is close to the maternal mortality rate in Africa (1).

Reconstructive surgery can mend the injury, and success rates are as high as 90% for uncomplicated cases. Two weeks or more of postoperative care is needed to ensure a successful outcome. Counselling and support are also important to address emotional damage and facilitate social reintegration.

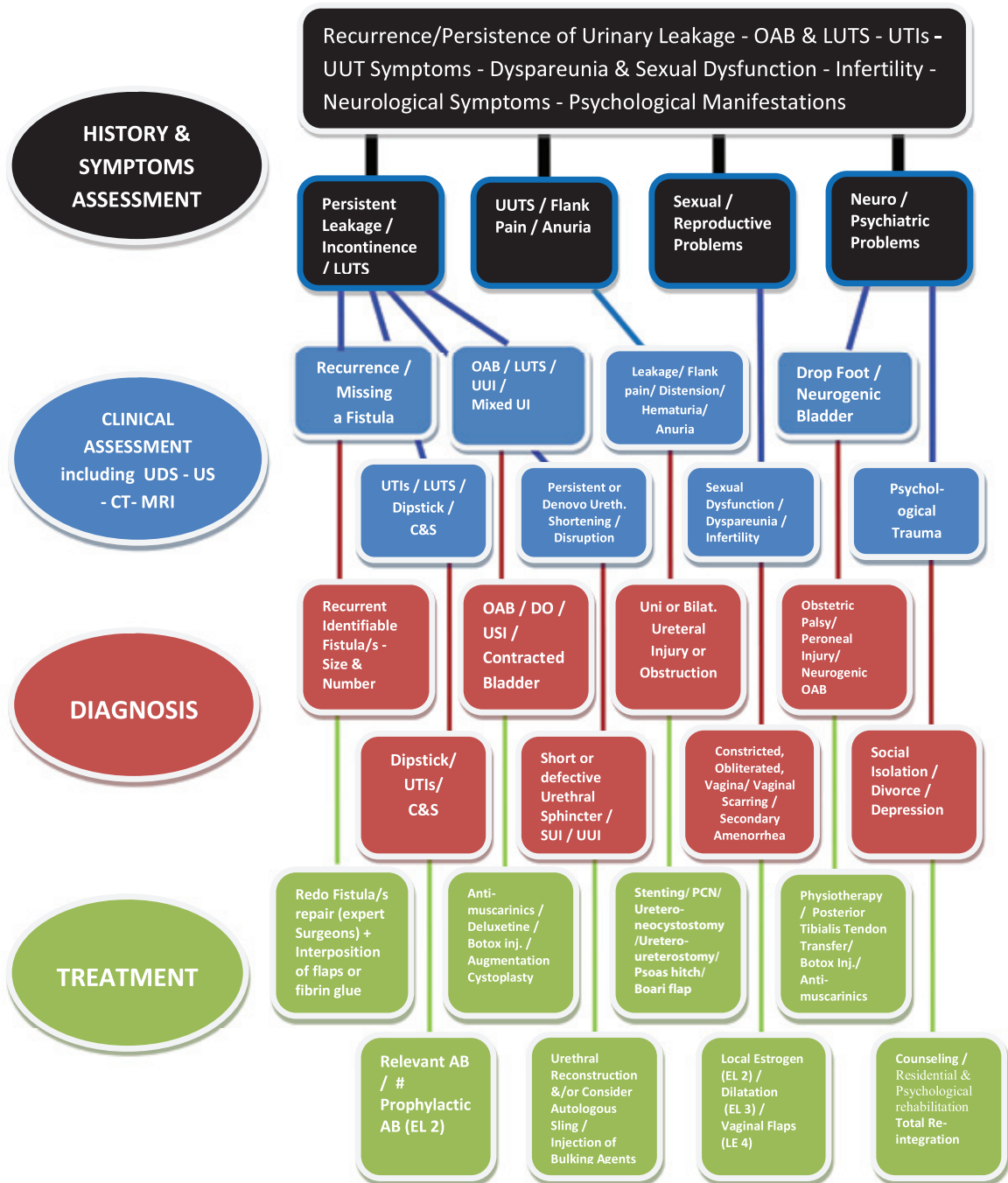
The complications of obstetric fistula formation and/or the complications of fistula repair are many and these include:

- Recurrent Fistula:
 - Success rate of uncomplicated vesicovaginal fistula (VVF) → 70-80%
 - Success rate of complicated VVF → 50-60%
- Infections: wound, urinary tract infections (UTI) and pyelonephritis and urosepsis
- Voiding Dysfunction (overactive bladder – incomplete micturition – Dysuria)
- Ureteric obstruction (ligation – fibrosis – injury)
- Outlet obstruction (meatal stenosis, urethral stricture, bladder neck obstruction [BNO])
- Bladder contracture
- Vaginal stenosis (overcorrection – fibrosis)
- Sexual dysfunction (vaginismus–dysparunia)
- Rare complications (granulomas – diverticulum formation)
- Neurological complications (foot drop – neurogenic bladder)
- Complex neuropathic bladder dysfunction and urethral sphincter incompetency often result, even if the fistula can be repaired successfully
- Psychological trauma (social isolation – divorce)

5.2 Publication Searches

This section is based on electronic searches of Medline, EMBASE (from 1980 to September 2010), the Cochrane Database of Systematic Reviews, Central Register of Controlled Trials (CENTRAL), Database of Abstracts of Reviews of Effects (DARE), Database of Health Technology Assessments, and Database of NHS Economic Evaluations, and the NICE website (all accessed October 2010); references included in identified systematic reviews were evaluated separately. Hand searching of recent (January to October, 2010) issues of major American, European and British journals in urology, gynaecology and urogynaecology was undertaken, to capture recent publications not yet included in the online databases. The International Continence Society (ICS), International Urogynecological Association (IUGA), American Urological Association (AUA), American Urogynecologic Society (AUGS) and the Society of Gynecologic Surgeons (SGS) conference proceedings for 2010 were also reviewed.

Management of Complicated Vaginal Fistula



Papers offering any relevant data were considered. This included systematic reviews, randomized and quasi-randomized trials, non-randomized cohort studies, case-control studies, longitudinal studies and case series or reports. Those papers considered for inclusion were assessed for quality where relevant, in terms of sequence generation, allocation concealment, blinding, handling of incomplete data, selective reporting and freedom from other biases. An evidence level (EL) was then assigned to all included studies according to the ICUD modified version of the Oxford Centre for Evidence-based Medicine system (2). Where quality was considered to be poor – as in most of the studies included in this section – the evidence level was reduced accordingly.

The review on obstetric fistulas was difficult because from the standpoint of evidence-based medicine, the literature on obstetric fistulas is not well represented. Most of the published articles were simple observational studies. There are no evidence-based guidelines or well-designed randomized controlled trials (RCTs). Within the relatively few papers published on obstetric fistulas in the developing world over the last few years, only two or three of these papers were considered to be “level 1 and 2” evidence. In this report we tried hard to indicate whether the conclusions are based on peer-reviewed papers in reputable journals or evidenced in book chapters or good abstracts.

5.3 Recurrent Fistula (*Persistent Incontinence*)

Fistulas can be closed successfully in 72–92% of cases. The definition of success, however, is often different when the perspectives of the patient and the surgeon are compared. “Success” to a fistula patient means complete restoration of urinary continence and control, whereas many surgeons define “success” as simply closing the fistula (1).

It is essential to establish defined criteria that will allow meaningful comparison of treatment outcomes. The patient-oriented criterion of continence restoration should be the goal when the outcomes of various fistula treatments are compared. Persistent incontinence, despite successful closure of the fistula, has been termed “the continence gap” (3).

A patient whose fistula is closed but who remains incontinent may be just as wet as a patient whose fistula closure operation failed. The estimates of persistent urinary incontinence after a successful closure of the fistula come from case series, ranging from 16.3% in a large retrospective review of patients by Wall *et al.* (4), to 33% in a small series of complex fistulas in which the proximal urethra was lost (5).

Adequate epidemiologic studies on the prevalence of fistula and its sequelae are scarce, and because long-term data on surgical outcomes are difficult to obtain, the prevalence of persistent incontinence after surgery appears to be severely underestimated (6,7,8).

Persistent urinary incontinence in patients after fistula repair is due to multiple factors including scarring, location of the fistula/s and surgical experience of the operator as well as failure to perform a sling operation or urethral reconstruction at the time of repair in patients likely to require such intervention.

The goal of fistula surgery should be restoration of continence and resumption of a full and active life on the part of the patient, not just closing the fistula.

5.4 Pathophysiology of Persistent Urinary Incontinence after Fistula Repair

Several possible etiological factors can be postulated in women who remain incontinent after successful fistula closure: loss of bladder tissues, massive damage to the mid-urethral continence mechanism, damage to attachments of the urethra, fibrosis and loss of compliance, neuropathy, etc.

Loss of bladder tissue is one of the main reasons why obstetric fistula repair is technically difficult. The loss of bladder tissue from pelvic ischemia during obstructed labour affects both the technique needed for, as well as the functional outcome of, fistula repair (2).

Although there are as yet no basic histological studies of the tissue surrounding obstetric fistulas, it seems clear that these tissues have themselves sustained significant damage during obstructed labour. The fistula itself develops in an area that becomes necrotic; but the tissues surrounding the fistula have also suffered varying degrees of ischemia. In some cases pressure necrosis may destroy virtually the entire bladder, so that if the defect can be closed at all, the afflicted woman is left with a remarkably small (30–50 ml) bladder that compliance may be altered by the extensive fibrotic changes that often take place. To date there have been few urodynamic studies reported on patients who have undergone successful fistula closure (9,10).

In the study by Carey *et al*, of 22 women with severe urinary incontinence after fistula closure, 9 had urodynamic stress incontinence with normal bladder compliance, 3 had urodynamic stress incontinence with poor bladder compliance, 9 had mixed incontinence, and one had voiding difficulty with incomplete bladder emptying and overflow (10). There is a great need for further investigation of these issues; unfortunately, those hospitals most likely to see large numbers of patients with obstetric fistulas also usually lack the resources for more advanced urologic investigation (10).

A number of patients with VVFs develop vesical calculi (11,12). Often these bladder stones develop in association with a foreign body in the vagina. After stone removal, the bladder should be allowed to heal prior to attempted fistula closure. If this is not done, there is substantial risk of postoperative infection and breakdown of the repair.

The ischemic changes produced by obstructed labour often have a devastating impact on urethral function. Complete urethral loss occurs in about 5% of fistula patients, with about 30% of fistula patients sustaining partial urethral injury. Goh *et al.* found that up to 63% of fistula patients have sustained some injury to the urethra (13).

In 1980, Ward reported that in a series of 1,789 patients, only 26 cases were inoperable; but in all 26 cases, urethral loss was present (14). There are no comparative surgical studies that evaluate differing techniques of urethral reconstruction in patients with obstetric fistulas. There are no data on postoperative urethral function. Work of this kind is badly needed.

Depending on the amount of tissue that is lost at the bladder base, the ureteral orifices can be found in bizarre locations, ranging from the lateral vaginal walls, all the way up to the level of the vesico-urethral junction and the pubic arch. Aberrant ureteral locations of this kind can easily be missed on clinical examination and are one cause of persistent incontinence after otherwise “successful” fistula closure. Standard urological tools such as ureteral stents are usually not available in hospitals in the developing world, and most of the surgeons who work in such hospitals are not trained in “urologic” techniques such as ureteral reimplantation (15).

The impaction of the fetal head is sometimes serious enough to cause ischemic injury to the bladder and to the vagina, which is likewise trapped between the two bony surfaces. These injured areas heal with varying degrees of scarring. Adetiloye and Dare detected fibrotic changes in 32% of fistula patients and minor vaginal wall fibrosis in another 36% in their sonographic study on a small number of patients (16).

The presence of vaginal scarring appears to be an important prognostic factor in determining the likelihood of both successful fistula closure, and also for the development of debilitating urinary stress incontinence (USI) after otherwise successful fistula repair.

Kelly and Kwast reported worsening surgical outcome in fistula patients who have vaginal scarring (17).

5.5 Assessment of Fistula

The number, size and location of the fistula/s are crucial for a successful repair that aims at a fully dry patient postoperatively. Clinically, it will be important to assess the number, size and location of the fistulas, the amount of fibrosis present, and any involvement of the ureters and or the urethra.

A complaint of persistent leakage by the patient needs to be evaluated. The first step is to assure that the fistula has been closed successfully. This can be done by placing a balloon catheter into the bladder, occluding the bladder neck and filling the bladder with a solution of water coloured with indigo carmine or methylene blue. If the fistula has not been closed successfully, the leakage should be readily apparent.

If deflating the balloon or moving it away from the bladder neck produces incontinence, the question may be differentiating transurethral incontinence from an urethrovaginal fistula. Where more advanced technological capabilities are available, diagnosing the presence of an urethrovaginal fistula may be facilitated by the use of a double-balloon catheter that allows occlusion of the urethra at each end and perfusion of the urethra through an opening between the two balloons. Most commonly, however, the diagnosis will have to be made on the basis of simple clinical testing by occluding the urethral meatus, asking the patient to strain, and seeing if there is leakage (2).

Limited data from urodynamic studies by Hilton (2) and by Carey, Goh *et al.* (10) suggest that detrusor overactivity and changes in bladder compliance are frequent causes of urinary incontinence in fistula patients with post-repair incontinence. This is in addition to the leakage resulting from successful closure but persistent intrinsic sphincter deficiency.

Examination of a patient (using methylene blue) during the fistula campaign in Niger.



5.6 Management of Recurrent Fistula

The most important concept is the recognition of the differences between simple and complex fistulas.

Vaginal surgery for small fistulas can be attempted under local anesthesia (20). Larger or more complex fistulas can be treated under spinal anesthesia, which is preferred over epidural or general anesthesia by many authors (21).

Operating by the abdominal route increases the cost and time of the operation, but is still often performed for some high fistulas where surgical access is problematic. Experienced fistula surgeons may be able to repair such defects vaginally. A retrospective study by Chigbu compared the outcome

of juxtacervical fistula through the vaginal or abdominal approach (22). Both approaches had similar cure rates and hospital stays, but the abdominal route was associated with a significantly higher need for blood transfusion.

General anesthesia is also more expensive, more complicated to administer, carries more risks, and should therefore be reserved for those patients who need an abdominal approach.

5.6.1 The simple fistula

Only about 20% of obstetric fistulas can be defined as simple. Simple fistulas are less than 3 cm in diameter, with no or only mild scarring and do not involve the urethra. The first prerequisite for successful fistula repair is meticulous attention to detail. In practiced hands, skilled fistula surgeons routinely achieve a closure rate of over 80% for simple fistulas at the time of first operation. Multiple papers reporting large case series support this contention (4,23–33).

A fairly general consensus concerning the basic principles of fistula repair was reached at the first Fistula Surgeons Experts Meeting at the World Health Organization (WHO) in Geneva in 2004. These principles can be summarized as follows:

- The best chance for successful fistula closure is at the first operation and closure rates tend to diminish with each subsequent attempt at operative repair. In their large series of 2,484 obstetric fistula patients, Hilton and Ward (1998) reported successful fistula closure in 82.8% of patients at the first attempt. Successful closure was achieved in only 65% of those patients who required two or more operations. Another unpublished series of 400 patients from the Addis Ababa Fistula Hospital reported a successful closure rate of 92% and urethral incontinence of 33% at the first operation, a closure rate of 73% and urethral incontinence rate of 50% at the second operation, and a closure rate of only 52% and urethral incontinence of 75% at the third operation (Browning, personal communication).
- The ureters should be identified and protected to ensure they are not cut or ligated during the fistula repair (if the site and size of the fistula puts them in proximity to the operative field).
- The fistula should be widely mobilized from the surrounding tissues at the time of repair.
- The fistula should be closed without tension on the site of repair.
- The repair must be ‘water-tight’. To ensure this, a dye test is performed intra-operatively and if there is still leakage, the repair is sutured again.
- After fistula repair, the bladder should be kept on free drainage for 10–14 days. There is some weak evidence that 10 days of drainage is just as effective as six-months follow-up (for fistulas of less than 3 cm diameter with mild to moderate scarring) (34). This change in catheter management could make a significant impact on the resources of hospitals where these operations are performed. If the time needed for postoperative bladder drainage could be reduced by 4 days, the capacity of the hospital to care for fistula patients would increase by 30% just from this gain in efficiency.

There is debate as to whether or not a Martius flap or other graft should be used in fistula repair. One retrospective paper compared the surgical outcomes of operations involving similar fistulas repaired with and without use of the Martius flap and demonstrated a higher successful closure rate when such a flap was employed (although cases were not randomized, so conclusions should be made with caution) (35).

Another more recent retrospective analysis evaluated 400 patients in whom comparable fistulas were repaired with and without the use of a flap. The analysis showed no differences between the two groups in closure rates or postoperative incontinence rates (24). Many experienced fistula surgeons now only use grafts under rare circumstances, such as when the urethra has been reconstructed, when the tissues are particularly poor, or if there have been multiple previous attempts at repair.

Once the fistula has been closed, the vagina is next repaired. When this has finished, a vaginal pack is placed, and the urinary catheter is left *in situ*. The following day, the vaginal pack is removed and the patient is encouraged to mobilize and eat. The bladder is left on continuous free drainage for 10–14 days.

Each day the “3-Ds” of postoperative fistula repair are checked. These are whether the patient is **d**ry, **d**rinking and the catheter is **d**raining. The patient has to be dry; that is the fistula repair must be intact; drinking to ensure adequate irrigation of the bladder; and draining, that is, the catheter is not blocked. If the catheter does become blocked and the bladder fills, the repair is at risk of breaking from increasing tension on the repair site. If the catheter does become blocked and the repair ruptures, this may often be rectified by continuous prolonged catheter drainage. By ensuring an empty and relaxed bladder, the sides of the defect may come together and close, but this can take as long as four weeks to occur. The success rate is about 70% in such cases, less if the defect involves the urethra.

Following these principles in the repair of simple fistulas, the surgeon can anticipate successful closure in 90% of the patients and a postoperative urethral incontinence rate (“closed but still wet”) of 10%.

5.6.2 The complex fistula

A complex obstetric fistula can be described as being larger than 3 cm, involving the urethra, and associated with reduced vaginal capacity from significant scarring and/or a reduced bladder volume. Sometimes the defect may be urethrovaginal, but more commonly both the urethra and bladder are involved and therefore the fistula is called an urethrovesicovaginal fistula (2).

Most of authors with extensive experience in the management of obstetric fistulas comment on the great difficulty in achieving postoperative continence in patients who have had extensive damage to the urethra, even if the defect itself has been closed successfully. Rates of postoperative urethral incontinence range between 6–50% (10,37). Often the diagnosis of postoperative incontinence is given only if the patient suffers from severe incontinence while walking. If rigorous questioning is used to exclude any leakage with coughing or other exertion, the rate of postoperative incontinence increases dramatically.

The four risk factors that lead to a high rate of incontinence following fistula repair are (38):

Urethral involvement

(Odds Ratio 8.4 for developing urethral incontinence post operatively.)

Large size of the fistula

(Odds ratio 1.34 for each centimetre increase in size of the defect.)

Severe vaginal scarring

(Odds Ratio 2.4 if the scarring is significant enough to prevent the introduction of a Sims speculum without relaxing episiotomies.)

Small bladder size

(Odds ratio 4.1, if the bladder capacity is less than 120 ml)

In repairing complex obstetric fistulas, the principles for simple fistula repair still apply but with the following additions:

- Exposure is more difficult. In complex cases the fistula may be obscured from view due to the presence of severe vaginal scarring. Such scarring often consists of a thick band of scar tissue on the posterior vaginal wall. Occasionally, the vagina has been completely occluded. Wide bilateral episiotomies may be required and where possible, the scar should be released from the lateral pelvic sidewalls. This will enable the fistula to be seen more clearly.
- The ureters should be identified and protected against possible injury, as in the case of a simple repair.
- The bladder and urethra should again be carefully mobilized. The tissues are often thin, scarred, and fragile in such cases. The mobilization often has to be extended along the lateral pelvic sidewalls and even on to the posterior aspect of the pubic symphysis in order to free the lateral and anterior bladder.
- The mobilization of tissues should be wide to ensure a tension-free closure.
- The utility of tissue flaps remains controversial. In some cases the use of tissue transposition techniques such as the Martius graft and various forms of sling operations are the mainstays of treatment.
- Using the fibrin glue could be useful in many cases, especially the recurrent cases with tissue damage. The use of fibrin glue as an interpositioning layer during the vaginal anatomical repair of complicated vaginal fistulas appears to be of great value as an alternative to the use of Martius flaps interpositioning. Decreasing the operative time and adding simplicity to the already complicated procedure are additional values of using this procedure (39).

Often, destruction to the vagina has been so extensive that rotational skin or myocutaneous flaps are required in order to cover the defect (26).

If these principles are applied, the success rate in fistula closure is high, but many women remain incontinent despite successful closure. In patients in whom all of the risk factors mentioned above are present, the postoperative incontinence rate may approach 100% (19,38).

In light of this dismal success rate, some surgeons now suggest that two further principles of repair be maintained:

Maintain the urethral length

A shortened urethra has been noted in post-repair fistula patients returning for further treatment of persistent urinary incontinence. An unpublished series of 72 patients with post-fistula repair incontinence found an average urethral length of 1.4 cm in these women. This suggests that continence might be improved if normal urethral length can be restored at the time of fistula closure. Vertical (as opposed to horizontal) repair of urethrovaginal fistulas has therefore been suggested. This appears to be possible in approximately 20% of such cases. In cases in which there is an urethrovesicovaginal defect, vertical repair of the urethral defect may improve success, while the vesical defect can be repaired either vertically or horizontally (2).

Support the urethra

For all urethral defects larger than 4 mm with a urethral remnant less than 2.5 cm, many fistula surgeons use an “anti-incontinence” procedure during the initial repair. Currently there are two widely used procedures. The first sutures the urethra/bladder neck to the periosteum of the pubic ramus in a type of suspension operation. The fascia or muscle of the bladder is sutured on either side of the bladder neck area to the posterior aspect of the symphysis pubis or the arcus tendineus (41).

The second procedure creates a sling of tissue to support the urethra. A pedicle of tissue is created on either side of the urethra from the lateral pelvic sidewall. In theory this involves use of the pubococcygeus muscle, but more often it is simply a pedicle of fibromuscular tissue or scar that can be harvested. The pedicles created on either side are then sutured together in the midline (19,38). If either of these two extra steps is used, the incontinence rate after closure of complex fistulas can be reduced from 100% to 50% (19).

Various authors have described neo-urethral reconstruction using bladder flaps (42,43). All of these operations are based upon trans-abdominal techniques such as that described by Elkins *et al.* (4). In this technique, a neo-urethra is created by mobilizing a flap from the anterior bladder, which is then rolled into a tube.

The anterior and lateral edges of the fistula are freed up and the space of Retzius is entered trans-vaginally beneath the pubic bone. The anterior bladder is pulled down into the vagina and mobilized. A 3–cm incision is made into the bladder and the anterior bladder wall is then rolled around a 16-Fr. Foley catheter, creating a tube.

The anterior surface of the neo-urethra is then sutured in two layers and the posterior edge of the fistula is closed transversely, also in two layers. The neo-urethra is reattached to the posterior edge of the pubic symphysis, and a Martius graft is placed before re-approximating the vaginal epithelium. In 18 of 20 cases, this technique resulted in fistula closure, but four women had severe stress incontinence postoperatively.

It is not known how many had mild incontinence. Neither of these surgical methods is ideal. Although they may create an anatomic urethra, often that urethra does not function normally. A further option in such cases is to create a “tube”, using either technique and then attempt to render the patient continent with the use of a urethral plug (45).

5.6.3 Advanced surgical techniques

A trans-abdominal approach could be used for large, supra-trigonal VVFs, associated ureterovaginal fistulas or if bladder augmentation and bladder neck reconstruction was required. The transvaginal route was preferred for small sub-trigonal fistulas. A combined abdominal and vaginal approach was used for large fistulas involving the trigone or the bladder neck. The surgical approach varied in each patient.

Interposition grafts or flaps were used when required (46). The overall surgical failure rate was 4.3%. The average operative time for layered closure was 72 minutes (45–130 minutes) and that for graft or interposition tissue repair: 100 minutes (90–165 minutes). The mean hospital stay was 9 days (6–17 days). There were no reported intra-operative complications. Postoperative complications were urinary tract infection, hematuria, wound infection and fever. None of the patients required blood transfusion. For the repair of small fistulas, surgeons did not use interpositional flaps but rather used the layered closure technique with a success rate of 97.1%. Complicated fistulas required repair by graft or tissue interposition and had a success rate of 94.8%, which is similar to the experience of other Indian centres (47). Risk factors for the failure of vesicovaginal surgery included previous failed repair, large-sized fistulas, fistulas involving the trigone or ureteral orifices, a small bladder capacity and unhealthy vesical urothelium at the time of surgery.

The majority of the large-sized fistulas were successfully repaired using the trans-abdominal technique described by O’Connor, with interposition of an omental flap (48). This technique works well except when the fistula extends up to the bladder neck or when its transverse diameter is too large to allow tension-free approximation.

5.6.4 Combined abdominal and vaginal approach

This technique may be required in complicated fistulas involving the bladder neck. In cases where urethral continuity is disrupted due to a fistula, a combined approach may be preferable. An abdominal route is used to repair the fistula and continuity of the urethra is established by anastomosing the urethra through the vaginal route.

5.6.5 Urinary diversion

Urinary diversion in developing countries is usually not a viable option since stoma appliances and catheters (in the case of continent urinary diversions) are often unavailable or are too expensive (49). In such cases, performing a diversion procedure merely moves the fistula to another part of the body. The end result of such surgery may be more stigmatizing in the local culture than the original injury.

Uretero-sigmoidostomy has been used as a surgical option in developing countries for many years. Many data show that both short- and long-term complications will arise and that surgeons must face this and treat them. On the other hand, a series of nine Tanzanian patients undergoing diversion found that results were acceptable and that patients had a marked improvement in their quality of life (50).

Urinary diversion with the creation of a sigmoid or rectal pouch is feasible in selected patients. Long-term data on outcome are not yet available. The risk of complications is rather high and managing complications adequately often requires diagnostic capabilities that are absent in developing countries.

5.6.6 Conclusions

The complications of vaginal fistula and its repair are multiple. The recurrence of fistula is the most frustrating.

Complications could be avoidable and repairable

- Adequate exposure of the operative field
- Repair should be: tension-free, watertight and uninfected
- Minimize bleeding and hematoma
- Avoid ureteral obstruction
- Interposition flap if required (omental or Martius flap or fibrin glue)
- Highest success (first attempt)
- Involvement of sphincteric mechanism (anti-incontinence procedure later)
- Associated vagino-rectal fistulas (should be repaired simultaneously with or without colostomy)

The advantage of having the fistula well repaired from the first time is crucial because success rate decreases with more attempts of repair:

- First repair success rate: 70–90%
- Second repair success rate: 50–60%
- More than two procedures: <40%

5.6.7 Recommendations

1. A care programme for failed repairs with persisting incontinence after a successful repair needs to be in place.
 2. Surgical treatment of postoperative stress incontinence should only be considered six months after fistula repair. (Grade D)
 3. Autologous material should be used when a graft or sling is required and there is no place for synthetic sling material. (Grade C)
 4. In order to prevent new fistulas in women who become pregnant after a fistula repair, waiting homes should be provided to ensure that each woman is able to have an elective caesarean section when she goes into labour. (Grade D)
 5. In recurrent identifiable fistula, make sure of the size and number. This type of fistula is better repaired by a well-experienced fistula surgeon. It is important to use tissue interpositioning like a Martius flap or fibrin glue. (Grade A)
-

5.7 Overactive Bladder after Vaginal Fistula Repair

The successful repair of a VVF can correct the anatomical defect, but it might not render the patient dry. Failure to store urine is another problem that may occur after vaginal fistula repair. This is caused by what is called the “Overactive Bladder Syndrome” (OAB).

According to the ICS definition of 2002, OAB is urgency, with or without urgency incontinence, usually with frequency and nocturia, if there is no proven infection or other obvious pathology (51).

Although persistent incontinence after fistula repair tends to be blamed on urethral dysfunction, a few urodynamic studies suggest that bladder dysfunction may play a role (10,18).

It is often assumed that OAB (a symptomatic diagnosis) is caused by detrusor overactivity (DO; urodynamic diagnosis), even if this does not always seem to be the case (52,53).

A small study of 22 women who underwent urodynamic studies to analyze post-repair incontinence revealed that 41% suffered from urodynamic stress incontinence; 41% had combined urodynamic stress incontinence and detrusor overactivity; 14% had a small non-compliant bladder; and 4% had a voiding disorder and overflow incontinence. In these cases, the incontinence may be so severe that the urethra functions only as an open “drain pipe” through which urine passes in a nearly continuous stream. The result is little different from the leakage that occurred through the original fistula (10).

Twenty-five percent of the patients who have their fistula successfully closed are incontinent (personal communication) In the Addis Ababa Fistula Hospital, they have two studies of newly closed fistula patients who are still wet and have urodynamics four weeks postoperatively provided they have a sterile urine. Overflow incontinence was excluded at the time of catheter removal and their dye test was negative. A total of 66 patients were studied in this group; 8 had USI, 2 had DOA, 51 had DOA and USI and 5 had overflow incontinence.

The second group are patients who have been discharged from the hospital wet, but with a closed fistula. The mean period following repair was 24 months. There were 186 patients in this group; 18 had USI, 2 had DOA, 121 had USI and DOA, 10 had a non-compliant bladder, 6 were normal and 29 with overflow incontinence.

Oxybutinin was not always available but for those in the mixed group who received two months of treatment 9 were cured and 62 improved in that they were dry at night. The urgency improved. They had on occasions a normal desire to void. Forty-five women in this group were dry with the use of a urethral plug (personal communication).

Urge-related bladder dysfunction can often be treated with low-cost antimuscarinic drugs. In cases where there has been extensive loss of bladder tissue or marked reduction in bladder compliance due to fibrosis, augmentation cystoplasty can be performed, usually by interposing a segment of bowel. In some case, urinary diversion may be indicated, but only after careful discussion of the issues involved with the patient.

Antimuscarinics block, more or less selectively, muscarinic receptors (54). The common view is that in OAB/DO, the drugs act by blocking the muscarinic receptors on the detrusor muscle, which are stimulated by acetylcholine (Ach), released from activated cholinergic (parasympathetic) nerves. Thereby, they decrease the ability of the bladder to contract.

However, antimuscarinic drugs act mainly during the storage phase, decreasing urgency and increasing bladder capacity, and during this phase, there is normally no parasympathetic input to the lower urinary tract (55).

5.7.1 Recommendations

Patients complaining of persistent leakage due to urgency incontinence or those who ended up with contracted bladder may try antimuscarinics, botulinum toxin A injection or even augmentation cystoplasty in small hypocompliant bladders. (Grade C)

5.8 Contracted Bladder as a Complication of VVF Repair

Although contracted bladder is a recognized complication of VVF, there is very little, if any, mention of this VVF in the literature. Nardos and colleagues mentioned that among 1,045 women who were subjected for repair of obstetric VVF, 17% suffered from small bladder capacity postoperatively. They also realized small bladder capacity is a risk factor for failure of VVF repair (56).

This problem was discussed during the Complications subcommittee meeting and we came to the following consensus. It is reasonable to believe that a contracted bladder results from substantial loss of bladder tissue during the pathogenesis of obstetric VVF. Repeated repair and tissue scarring may add to this problem. It is very difficult to diagnose this problem pre-operatively except in very obvious cases.

Every effort should be made during the repair of the VVF to spare bladder tissue. Contracted bladder can be one of the causes of persistent incontinence after successful repair of VVF. At that time, diagnosis should rely on filling cystometrogram, if available, which typically should show low bladder compliance and small cystometric capacity.

It is wiser to postpone treatment until successful repair of the fistula is achieved. Nevertheless, a group in India attempted to repair complex VVF and to augment bladder with the ileum during the same procedure. Their repairs were successful in all the four cases they treated (57).

It has to be mentioned that in three of these cases, the fistula was obstetric in origin and one secondary to genital tuberculosis. Eilber and colleagues suggested that an abdominal approach to repair the fistula could be utilized if bladder augmentation is planned simultaneously (58).

Treatment should follow the same principles and indications of treating contracted bladder of other etiologies. The only treatment option available is augmentation cystoplasty since pharmacological manipulation, detrusor botulinum toxin injection, and neuromodulation is unlikely to work because the problem is primarily myogenic.

5.8.1 Recommendations

Contracted bladder is a recognized complication of VVF and it is a risk factor of repair failure. (EL4)

Every effort should be made during the repair of the fistula to preserve bladder tissue. (EL4)

Contracted bladder can be a cause persistent incontinence after successful closure of the fistula. (EL4)

Diagnosis should rely on urodynamics whether multichannel or eyeball. (EL4)

Augmentation cystoplasty may be the only reasonable option in extreme cases. (EL 4)

Further research on this topic is required. (EL4)

5.9 Urinary Tract Infection

On rare occasions urogenital fistula may be causally related to infective pathologies (e.g. lymphogranuloma venereum, schistosomiasis, tuberculosis, actinomycosis, measles or noma vaginae) (2); in one series of 2,484 obstetric fistula cases, 7 (0.3%) were thought to be primarily of infective etiology (18).

In general however, it is considered that a urinary tract infection (UTI) is relatively uncommon in women with fistula, in view of the free drainage of urine from the bladder, and the rarity with which such patients suffer voiding dysfunctions. A UTI may however be seen as a complication of surgical repair of fistula or of the prolonged catheter drainage that usually follows such procedures.

5.9.1 Literature review

The literature on the subject of UTI associated with fistula repair is extremely limited. The literature searches documented above identified 5,488 papers relating to urogenital fistula; 1,961 of which related to surgery; 114,285 references related to UTI, but after removal of duplicates only 127 indicated

UTI following fistula surgery. Of the latter group, only 10 could be considered to include data of even marginal relevance to the topic of this review, of which only one was a randomized controlled trial (RCT).

Additional hand searching of 2010 journals and conference abstracts identified no further relevant papers. These papers are summarized in **Table 1**, along with evidence levels (EL) assigned according to the ICUD modified version of the Oxford Centre for Evidence-Based Medicine system (2).

TABLE 1 Detail of Publications Including Reference to UTI prior to or Following Fistula

| Author, Year | Study Type | Details | Participants | Outcomes | Evidence Level | Comments |
|--|-------------|--|--------------|--|----------------|--|
| Tomlinson <i>et al.</i> , 1998 (61) | RCT | Ampicillin vs. no prophylaxis | 81 | Reduced UTI & antibiotics postop but no difference in fistula closure | 2 | Single blinded study; methods of randomization not specified; no sample size calculation |
| Chigbu <i>et al.</i> , 2006 (22) | Non-RCT | Juxtacervical fistula -51 abdominal vs. 28 vaginal | 78 | Higher rate of transfusion with abdominal; similar rates of fistula closure and postop UTI (1% with both routes) | 3 | |
| Vidal-Mora <i>et al.</i> , 2009 (68) | Case series | Retro-spective review of 9 cases over laparoscopically treated fistula over 13 years | 9 | 1 UTI (11%) | 4 | |
| Otsuka <i>et al.</i> , 2008 (64) | Case series | Series of laparoscopic transperitoneal VVF repair | 6 | Retrospective review of 6/7 cases completed laparoscopically; 1 (17%) UTI | 4 | Mean operating time nearly 5 hours! |
| Roberto Martinez <i>et al.</i> , 2007 (66) | Case series | Retrospective review of 27 women treated over 13 years | 27 | UTI commonest complication (7%) | 4 | Only 71% closure rate |

RCT = randomized controlled trials, UTI = urinary tract infections

continued on **page 144**

TABLE 1 Detail of Publications Including Reference to UTI prior to or Following Fistula, *Cont'd*

| Author, Year | Study Type | Details | Participants | Outcomes | Evidence Level | Comments |
|--|-------------|---|--------------|---|----------------|---|
| Shelbaia <i>et al.</i> , 2007 (67) | Case series | Retrospective review; all surgical cases | 20 | No UTI reported (0%) | 4 | |
| Ansquer <i>et al.</i> , 2006 (62) | Case series | Series of Latzko procedure | 11 | No operative complications; only postop complication (1(9%) UTI) | 4 | Retrospective case series of 11 cases over 14 years |
| Ayed <i>et al.</i> , 2006 (69) | Case series | Multivariate analysis | 73 | UTI prior to repair was a significant adverse factor (P=0.03), although OR n.s. 2.72 (0.69, 12.1) | 4 | Retrospective case series of cases over 17 years; 73 women had 97 procedures (41% obstetric etiology) |
| el-Lateef Moharram <i>et al.</i> , 2004 (63) | Case series | Series of transvesical repairs with fat graft | 26 | All continent; 15 had urgency, 3 (12%) recurrent UTI | 4 | |
| Ou <i>et al.</i> , 2004 (65) | | Retrospective review of 16 women; variety of operative routes | 16 | 1/16 (1/6 with vaginal repair) developed UTI (6%;17%) | 4 | Describe laparoscopic approach but only 2 cases |

RCT = randomized controlled trials, UTI = urinary tract infections

5.9.2 Discussion

No systematic reviews or meta-analyses were identified from the literature search. Only one RCT was identified (5); the majority of papers were uncontrolled retrospective case series, looking primarily at surgical techniques and outcomes in terms of continence.

Several mention the occurrence of UTI, but allow nothing more than a crude estimate of the incidence of the complication in the particular circumstances described. The rate of infection in these case series was between 0% and 17%, with an overall rate of 5% out of the 193 women included (22,62–68).

Ayed *et al.*, on the basis of a multivariate analysis of a retrospective cohort, reported that UTI prior to repair was an adverse prognostic factor for successful surgery ($p=0.03$); the OR however was not significant (OR 2.72; 95%CI 0.69, 12.1) making the conclusions of the study of limited significance (69). In a small series of post-hysterectomy fistulas; managed by laparoscopic, open abdominal, or vaginal repair; Ou *et al.* reported only a single episode of UTI following a vaginal procedure (1 out of 6 cases), and none following the alternative approaches (65).

Chigbu *et al.* reported no difference in the rate of successful fistula closure, or of postoperative UTI between abdominal and vaginal repair procedures in women with juxtacervical fistulas (22). The numbers of patients included, and the methodology used in these reports makes conclusions on the relative rate of UTI following different repair procedures inappropriate.

In the only RCT identified on this topic, Tomlinson compared intra-operative prophylactic ampicillin with no treatment, and found that although the rate of UTI, and the use of antibiotics postoperatively were higher in the control group (OR 0.7), the rate of successful closure was no different (61). The data from this study have been incorporated into Forest plots using Review Manager V5 and are illustrated in Figures 1–3.

FIGURE 1

Forest plot of comparison:
1 Antibiotics vs.
no prophylaxis, outcome:
1.1 Incontinence

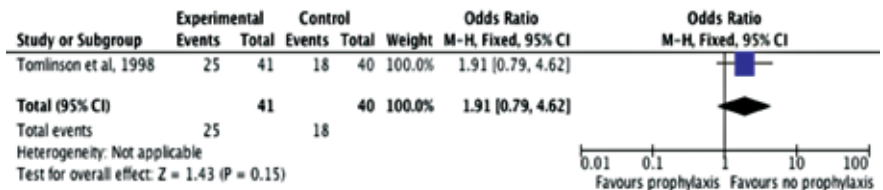


FIGURE 2

Forest plot of comparison:
1 Antibiotics vs.
no prophylaxis, outcome:
1.2 Failure of fistula
closure

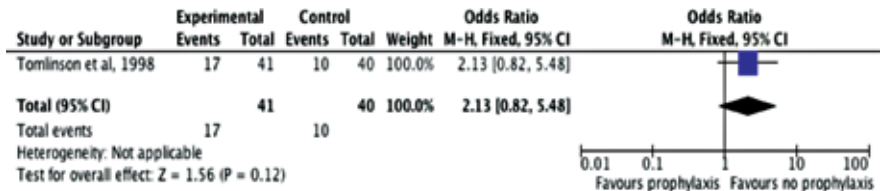
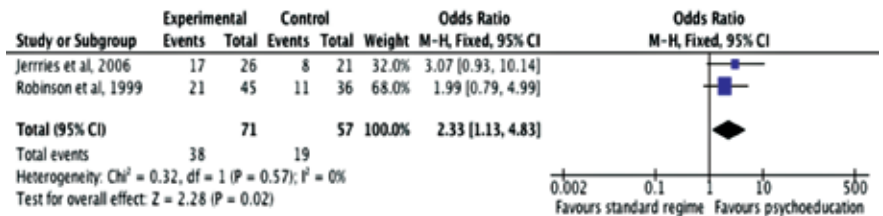


FIGURE 3

Forest plot of comparison:
3 Dilatation plus psycho-
educational support vs.
dilatation alone, outcome:
3.2 Compliance with
treatment.

*n.b. Robinson et al, 1999
reports responses (81) not
patients (32)*



5.9.3 Conclusions

The literature on this topic is limited, and the majority is of inadequate scientific value to allow meaningful evidence statements and recommendations.

The evidence from a single study that UTI prior to fistula repair may be a poor prognostic feature is of doubtful significance. (EL4)

There is no evidence available to adequately determine whether the rate of UTI postoperatively varies between different surgical approaches or non-surgical management techniques. (EL4)

The use of intra-operative antibiotic prophylaxis has been shown to reduce the rate of UTI and antibiotic prescribing postoperatively following fistula repair, but has not been shown to influence the rate of successful fistula closure. (EL2)

5.10 Contracted Vagina, Dyspareunia, and Sexual Dysfunction

The problem of cicatrization in association with vesicovaginal and urethrovaginal fistulas is well recognized, and known to be more associated with obstetric fistulas related to obstructed labour, or to post-radiation fistulas than to other etiologies. In the first case, acute ischemia occurs as a result of prolonged unrelieved pressure on the bladder base and urethra by the fetal presenting part. In the second case, progressive devascularisation occurs as a result of chronic endarteritis, which may be progressive over several decades (70).

The extent of scar has been looked on as an important predictor of surgical success, (13,71) and has been incorporated into fistula classification systems (72,73). Muleta and colleagues reported severe vaginal scarring or obliteration in 14.9% of 14,373 women undergoing obstetric fistula repair in Ethiopia (74). The impact that this scarring may have on subsequent sexual function has been little investigated.

It is well recognized that many women report sexual symptoms following any form of pelvic surgery; this is particularly problematic following vaginal surgery, including that for urinary incontinence and pelvic organ prolapse. Whether the surgery is causally related to the symptoms is however less certain. In a study of quality of life four years after anatomically successful repair, both urinary and sexual symptoms were found to be common (75) and were reported with approximately twice the prevalence of the local population of comparable age (76).

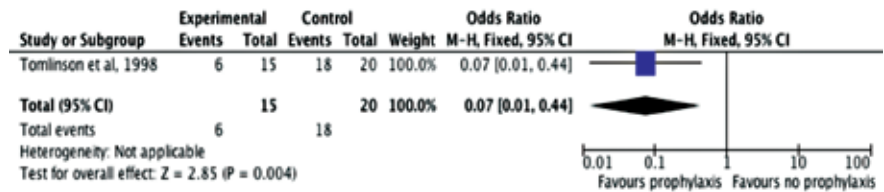
Whilst the residual urinary symptoms had little impact on quality of life for the majority of women, the persistent sexual symptoms were reported as “quite a problem” or “a serious problem” by 27% (75). No comparable prevalence data for sexual dysfunction in obstetric fistula patients has been identified from the literature.

5.10.1 Literature review

The literature searches identified 5,488 papers related to urogenital fistula, 1,961 of which related to surgery; 272,261 related to dyspareunia, sexual dysfunction, vaginal constriction, scarring, cicatrization, or obliteration; of which only 88 related to these problems following fistula surgery, after removal of duplicates (see **Figure 4**). Additional hand searching of 2010 journals and conference abstracts identified a further 25 studies of which only 2 were of relevance. Overall, only 7 references were identified which contained any information of any relevance to the topic of this review; of these, none were RCTs and only one included any comparative data.

FIGURE 4

Forest plot of comparison: 1
Antibiotics vs. no prophylaxis,
outcome: 1.3 Infection
(positive CSU day 10).



One tangentially relevant systematic review was identified from the electronic literature search, and a second from hand searching; both related to interventions for the physical aspects of sexual dysfunction in women following pelvic radiotherapy, rather than being specifically related to patients with urogenital fistula (77,78). The relevant papers are summarized in **Table 2**. Papers from the identified systematic reviews are summarized individually in the evidence table. Evidence levels (EL) are assigned according to the ICUD modified version of the Oxford Centre for Evidence-Based Medicine system (2).

TABLE 2 Detail of Publications Including Reference to Vaginal Scarring, Dyspareunia or Sexual Dysfunction Following Fistula Repair

| Author, Year | Study Type | Details | Participants | Outcomes | Evidence Level | Comments |
|--------------------------------------|------------------------------------|--|-------------------|---|----------------|---|
| Johnson <i>et al.</i> , 2010 (78) | Systematic review or meta-analysis | Dilatation +/- support | 432 in 11 studies | Routine dilatation not supported by good evidence; used early may cause damage; ;later may cause some stretching (no change in sexual function) | 1 | |
| Denton <i>et al.</i> , 2003 (77) | Systematic review or meta-analysis | Studies examined effects of dilators, estrogen and benzydamine | 225 in 4 studies | Stents (dilators) appear to be successful in one non-RCT. Benzydamine and vaginal estrogen promising in 3 RCTs of low quality. | 1 | n.b. examined sexual difficulty following pelvic radiation. All included studies of poor quality, and published up to 40 years ago |
| Jeffries <i>et al.</i> , 2006 (86) | RCT | Dilators vs. dilators + psychoeducational support (motivational behavioural skills teaching) | 47; 26/21 | Compliance with dilators | 2 | |
| Robinson <i>et al.</i> , 1999 (80) | RCT | Dilators + information vs. dilators + information + psychoeducational support (motivational behavioural skills teaching) | 32 | Sexual health scores; compliance with treatment | 2 | Numbers difficult to assess, and conclusions, especially about the influence of age on outcome questionable (see Johnson <i>et al.</i> , 2010 syst review). Gives 81 responses in 32 women! |
| Volterrani <i>et al.</i> , 1987 (85) | RCT | Benzydmaine vs. placebo | 32 | Subjective improvement of vaginal symptoms using baseline and post-treatment scores and objective assessment with colposcopy for both groups. | 2 | |

continued on page 149

TABLE 2 Detail of Publications Including Reference to Vaginal Scarring, Dyspareunia or Sexual Dysfunction Following Fistula Repair, *Cont'd*

| Author, Year | Study Type | Details | Participants | Outcomes | Evidence Level | Comments |
|---------------------------------------|-----------------------------|--|--------------|---|----------------|--|
| Bentivoglio <i>et al.</i> , 1981 (84) | RCT | Benzydmaine vs. placebo | 30 | Improvement in the symptoms of acute vaginitis using a baseline and post-treatment assessment with a three-point score | 2 | |
| Pitkin <i>et al.</i> , 1971 (83) | RCT | Intravaginal dienestrol vs. placebo | 93; 44/49 | The development of vaginal bleeding, dyspareunia, stenosis and assessment of vaginal epithelium | 2 | |
| Browning <i>et al.</i> , 2010 (185) | Non-randomized cohort study | Examination of relevance of FGC to fistula | 492; 255/237 | Higher use of sling at time of repair and less ureteric catheterization in cases than controls. Type I and II FGC (and scarring of fistula) were not seen as independent risk factors | 3 | |
| Sobotkowski <i>et al.</i> , 2006 (81) | Non-randomized cohort study | Mitomycin applied to vaginal vault in women following RT for ca cx | 31 | Vaginal length | 3 | Allocation unclear. No difference in vaginal length with treatment. |
| Decruze <i>et al.</i> , 1999 (79) | Case-controlled series | Vaginal stent vs. sexual intercourse | 70 | The development of vaginal stenosis assessed clinically at 1 year. | 3 | Authors own design of stent; describe all failures as being patients' incorrect use of the device! |
| Chow <i>et al.</i> , 2010 (186) | Case series | Series of Latzko procedures | 17 | No reports of sexual dysfunction | 4 | It is not certain all were sexually active (28–80 yo) |

continued on **page 150**

TABLE 2 Detail of Publications Including Reference to Vaginal Scarring, Dyspareunia or Sexual Dysfunction Following Fistula Repair. *Cont'd*

| Author, Year | Study Type | Details | Participants | Outcomes | Evidence Level | Comments |
|---------------------------------------|-------------|--|--------------|---|----------------|----------|
| Capes <i>et al.</i> (abs), 2010 (187) | Case series | 305 patients; 205/283 successfully treated | 283 | Of the 205 with closed fistula, 43 (21%) had SUI, 5 (2.4%) DI, and 7 (3.4%) mixed incontinence, and 150 (73.2%) were continent or dry. Scarring unrelated to outcome. | 4 | |
| Muleta <i>et al.</i> , 2010 (74) | Case series | Obstetric fistula from Ethiopia | 14,298 | Severe scarring or obliteration in 14.9% | 3 | |
| Dolan <i>et al.</i> , 2008 (75) | Case series | Largely surgical fistula in the UK | 31 | BFLUTS questionnaire at median of 4 years after repair | 3 | |
| Goh <i>et al.</i> , 2008 (13) | Case series | Obstetric fistula assessed by Goh classification | 987 | 960/987 successfully closed; 229 (24%) reported incontinence. Fistula close to EUM, circumferential fistulas, and those with significant scarring were most likely to fail. | 3 | |
| Flynn <i>et al.</i> , 2004 (188) | Case series | Largely posthysterectomy fistulas, treated | 40 | 85% sexually active at 3 months; 2 deep dyspareunia | 4 | |

5.10.2 Discussion

Both systematic reviews identified examined interventions for the physical aspects of sexual dysfunction in women following pelvic radiotherapy (77,78). Only seven useful studies were identified in these reviews, investigating the effects of vaginal dilators (or stents or specula) (79–81), intravaginal estrogen (83), and benzydamine douches (84,85). The latter compound is an anti-inflammatory, which acts directly on inflamed tissues by stabilizing cells and lysosomal membranes and by inhibiting the synthesis of prostaglandins.

It is used topically and is well absorbed through the vaginal skin reaching higher concentrations in the underlying inflamed tissue than after oral administration. It also has analgesic, local anaesthetic and antimicrobial effects (77). Each of these interventions might therefore be of potential value in the face of sexual dysfunction following fistula repair surgery.

Two studies (both from the same unit) investigated the effects of a programme of psycho-educational support along with the use of vaginal dilators (80,86). Both reported an increase in compliance with the use of dilators (see **Figure 5**), although no difference in sexual function scores was found (80). Although one study has reported a reduction in findings of vaginal stenosis (see **Figure 6**) (79), others have not confirmed significant changes in vaginal anatomy (80). In the context of radiotherapy, both systematic reviews emphasize the poor quality of available evidence (77,78), but draw different conclusions about the appropriateness of continuing to recommend routine dilation during treatment. One suggests that intervention may plausibly be associated with greater scar formation, rather than less, particularly if used in the acute phase of treatment (78).

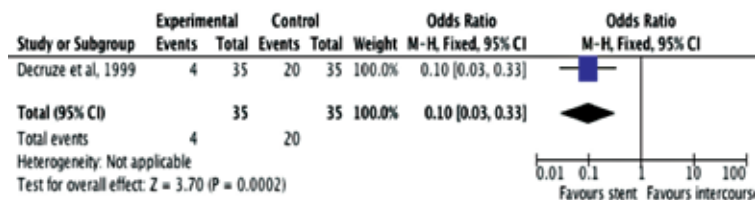
Two RCTs investigated the use of benzydamine (84,85) and one intravaginal estrogen to reduce vaginal symptoms and sexual dysfunction following radiotherapy (83). Each of these reports found improvements in vaginal symptoms, although both were underpowered, and of limited quality (see **Figures 3, 5 and 6**) (77).

Secondary amenorrhea is commonly seen in obstetric fistula patients. Whether this reflects the tissue loss within the pelvis or a hypothalamic influence as a result of the physical and emotional effects of a traumatic labour, stillbirth and fistula development is not clear. The live-birth rate has been reported to be no more than 10% in obstetric fistula patients (6,74) so estrogen deficiency as a result of lactation is unlikely to be a significant factor.

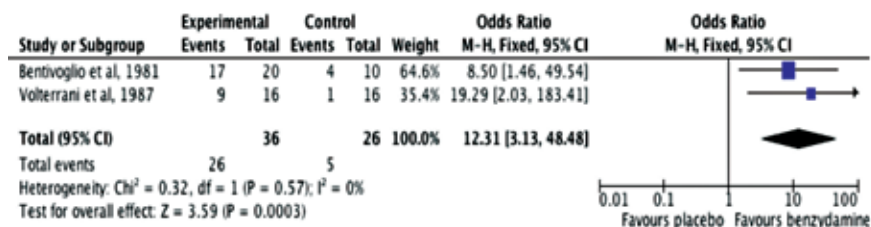
A study from Nigeria found that 44% of patients were amenorrheic at the time of referral, and the average delay between the associated pregnancy and presentation was around two years; 39% had resumed menstruation and their average delay to presentation was averaged over four years (60). This might be taken to imply that the natural history of any hypothalamic suppressive effect of the development of a fistula tends towards spontaneous resolution after two years, even if the fistula remains untreated. This in turn tends to indicate that whilst scarring might be a significant contributor, estrogen deficiency is the more significant influence. The possible benefits seen in vaginal symptoms in the irradiated vagina suggest that intravaginal estrogen might be a useful adjunct to treatment of sexual dysfunction following fistula repair.

FIGURE 5

Forest plot of comparison:
4 Vaginal dilator (stent)
vs. no treatment or normal
intercourse, outcome:
4.1 Vaginal stenosis.

**FIGURE 6**

Forest plot of comparison:
2 Benzylamine vs. placebo,
outcome: 2.1 Subjective
improvement in symptoms



5.10.3 Conclusions

1. Vaginal scarring is a common finding in obstetric fistula patients, and has been commonly (but inconsistently) linked to poor prognosis for surgical outcome. (EL3)

2. Persistent symptoms of sexual dysfunction are common following fistula repair surgery, and have a significant impact on the quality of life for a significant number of women. This has been demonstrated from a longitudinal cohort study of largely surgical fistula patients (EL3), and seems likely to be a substantially greater problem in obstetric fistula patients where tissue loss and cicatrization are seen more frequently and more extensively (EL4).

3. There is no evidence on the use of vaginal dilators in the management of scarring associated with obstetric VVF. Extrapolated data from post-radiotherapy vaginal stenosis may or may not be appropriate. Compliance is likely to be a problem with this approach to management, although there is evidence that additional psycho-educational support may improve compliance (EL2); data on effectiveness are inconsistent (EL3).

4. Data on alternative non-surgical modalities of treatment for vaginal and sexual symptoms following obstetric fistula repair are also limited. Extrapolation from post-radiotherapy vaginal stenosis using intravaginal estrogen or benzydamine douches are encouraging, but supported by only limited RCT data (EL2).

5.11 Urethral Complications of Vaginal Fistula Repair

5.11.1 Discussion

Urethral complications of obstetric genitourinary fistula can occur as a complication of genitourinary fistula repair or can be associated with it. These complications include, urethrovaginal fistula, urinary incontinence, and obstruction.

Urethrovaginal fistula is a distinct type of fistula that has to be differentiated from VVF. It can occur as a standalone fistula or can accompany a VVF. Furthermore, it can extend to involve the bladder neck and the trigone. Incontinence and obstruction are other consequences that can occur after the repair of genitourinary fistulas (60,87).

Obstructed labour is the main cause of obstetric urethrovaginal fistula. The vast majority of this type of fistula is present in the developing world (60,88). Extensive ischemic necrosis of the urethra and the vagina occurs during obstructed labour due to compression of these tissues between the fetus head and the symphysis pubis.

It usually involves the bladder neck and the trigone as well (88). Nevertheless, although rare, it is still reported in the industrialized world. In fact, obstetric urethrovaginal fistula is still the most common type of urethrovaginal fistula. Apart from urethral involvement in genitourinary fistula, urethral injury can be of iatrogenic origin during the repair of genito-urinary fistula (89).

Stress urinary incontinence (SUI) can result after treating urethrovaginal patients. It is not clear from the literature whether SUI that occurs after the repair of urethrovaginal fistula in over half of the patients is secondary to repair of the fistula or was a sequel of the original pathology.

Although not well documented, the consensus of the Complication Committee of the VVF Consultation was that it is reasonable to assume that stress incontinence in these circumstances is mostly due to intrinsic sphincteric deficiency. On contrast, urethral stenosis and obstructive symptoms can result from the repair of urethra-vaginal fistula (90).

The exact incidence of different urethral complications of VVF is very difficult to determine. In one report from Sierra Leone, examination of 505 patients with genitourinary fistula showed that only 56% of these patients were judged to have normal urethra (88). In another study, urethrovaginal fistula compromised 2.8% of 2484 patients presented with urogenital fistula, most of them are of obstetric etiology (92.2%) (60). Similarly, Raassen and others found that urethral involvement occurred in 5% of patients with obstetric urogenital fistulas (90).

Stress urinary incontinence is the most prevalent complication of the repair of genitourinary fistula in one of the studies. It occurred in 10% of the patients. Unfortunately, it was not further analyzed as regards the etiology of this incontinence (89).

In another study, 55% of 58 patients complained of persistent incontinence after successful closure of genitourinary fistula. Urodynamics showed that 31% had stress incontinence, 4% due to detrusor overactivity and 20% had mixed incontinence (91).

Apparently, the original site of the fistula and whether it involves the urethral closure mechanism, has a direct relation to the post-repair occurrence of stress urinary incontinence. Raassen and colleagues demonstrated that if the original site of the urogenital fistula is more than 5 cm from the external urethral meatus (Type I of Waaldijk classification), the incidence of postoperative stress urinary incontinence is significantly lower than if the fistula is less than 5 cm from the external meatus (Type II) (90).

Involvement of the urethral closing mechanism and circumferential fistula (with complete destruction of the bladder neck) leads to significantly higher incidence of postoperative stress urinary incontinence as compared to those cases without involvement of urethral closure mechanism and those without circumferential fistula (Table 3) (90).

TABLE 3 Outcome of Postoperative Dye Test and Urinary Continence (Stress) Test Per Fistula Type

| Classification | Total (N) | 14 Days Postoperative | | |
|----------------|-----------|-------------------------|---|-------------------------|
| | | Positive dye test N (%) | Positive urinary continence (stress) test N (%) | Total incontinent N (%) |
| I | 122 | 8 (7.4) | 2 (1.6) | 10 (8.2) |
| IIaa | 327 | 30 (8.9) | 24 (7.3) | 54 (16.5) |
| IIab | 61 | 10 (16.4) | 15 (24.6) | 25 (45.9) |
| IIba | 21 | 3 (14.3) | 3 (14.3) | 6 (28.6) |
| IIIBb | 8 | 0 (0.0) | 4 (50.0) | 4 (50.0) |
| III | 26 | 1 (4.0) | 0 (0.0) | 1 (4.0) |
| Total | 565 | 52 (9.2) | 48 (9.3) | 100 (17.7) |

Quoted from Raassen and colleagues. (89)

Urethral injury occurred in 2% of the patients during the repair of the genitourinary fistula. Urethral stenosis was reported in 5.63% of patients after repair of urethrovaginal fistula (89).

Presentation is dependent on the site of the fistula along the urethra and the involvement of the bladder neck and the bladder. If the urethro-vaginal fistula is large or if there is an involvement of the bladder neck and the bladder, continuous incontinence occur as in the cases of VVF.

On the other hand, if the fistula is proximal in position, patient may present with stress urinary incontinence. Distal fistula can be completely asymptomatic or may be associated with splayed urinary stream. Positional wetting, which is incontinence on rising after voiding due to filling of the vagina with urine during voiding may also occur in proximal fistula (87).

Most of urethral fistulas are easy to diagnose and can be identified with vaginal speculum examination. Large fistulas can be palpated manually. Identification of smaller fistulas can be facilitated by filling the bladder with methylene blue-dyed saline. A metallic sound can also be used to facilitate identification of the fistula. Other associated genitourinary fistulas should be sought. Urine analysis should be performed as well. Urethrocystoscopy is a good adjunct to determine the involvement of the bladder neck and the trigone (87).

The involvement of the urethra seems to decrease the success rate of the management of genitourinary fistula. In a report from Sierra Leone on 505 patients with obstetric genitourinary fistula, patients with urethra-vaginal fistula behaved worse than the rest of the cohort. The success rate of surgical repair was 73%, 92%, and 63% for juxta-cervical, midvaginal and juxta-urethral respectively (89).

When patients were categorized according to urethral status: success rate was 84%, 51% and 71% for patients with intact, partially damaged, and complete destruction of urethra, respectively (89). In contrast, another group couldn't find this influence of urethral involvement on the repair results. In that study, the patients were categorized according to Waaldijk classification. Involvement of the urethra didn't influence the results of the repair in a multivariate analysis (90).

Pushkar and colleagues suggested to repair the urethrovaginal fistula by circumferential incision involving the fistula. The urethra is then mobilized and closed transversely to avoid constriction of the urethra. They advised against extensive trimming of the fistula edges since there is usually minimal tissues left for repair. They tested the urethra for any residual opening using metallic sound inserted in the urethra. A second layer from the periurethral tissues was placed before closing the vagina. A urethral catheter is placed for 6–9 days. Using this technique obtained a success rate of 90.14%. Recurrent fistulas were re-repaired and were successful in all but one patient (87).

The use of intervening layer is always advisable. Martius labial fat pad flap are the most easily accessible and the most used flaps (87,92,93). Others have described the use of peritoneal flaps with similar success to that of Martius flap although most of the fistulas in that report were non-obstetric. They have shown as well that the use of full thickness labial flaps is feasible. Nevertheless, they used that particular technique in only three patients (59).

Bruce and colleagues have described the use of rectus abdominis muscle flap as intervening layer between the urethral and the vaginal layers (94). The use of autologous fibrin glue has been shown to function equally to the use of Martius graft in complex genitourinary fistula. Clear advantage of this was shown in the form of decreasing the complexity of an already complex procedure and decreasing operative time. Additionally, it doesn't preclude the use of Martius graft simultaneously (39).

Stress urinary incontinence that develops after urethrovaginal fistula repair can be treated with suburethral sling, whether autologous or synthetic. Most of the patients in one study (59.46%) were objectively cured, while 32.43% expressed they were satisfied, and 8.11% of the patients remained incontinent (87). Another group advocated doing video-urodynamics prior to surgical intervention. If stress urinary incontinence is diagnosed, the patient is offered pubovaginal sling during the same procedure of repairing the urethrovaginal fistula (12).

Hilton and colleagues reported their preliminary experience of treating sphincteric incontinence following repair of urethrovaginal fistula in six patients with autologous fat injection. Two patients were cured, two improved, and two didn't benefit from the procedure (96). The Complication Subcommittee of the VVF Consultation felt that it is safer to use autologous pubovaginal sling to repair stress urinary incontinence in these patients, whether simultaneously with the original repair, or later on.

5.11.2 Conclusion

The level of evidence in the literature regarding urethral complications of VVF is quite low. It appears that most urethral complications of VVF are preventable. These complications are urethrovaginal fistula, urinary incontinence, and urethral obstruction. Diagnosis of the urethrovaginal fistula is mainly dependant on vaginal examination and can be facilitated by the use of methylene blue and urethral sound. Persistent urinary incontinence after successful repair of VVF is mostly due to ISD but can be secondary to overactive bladder.

Treatment of urethrovaginal fistula is always surgical, using anatomical closure with the use of tissue interpositioning. The use of fibrin glue can improve the results. Stress urinary incontinence is best treated with pubovaginal sling using autologous material such as the rectus sheath or fascia lata.

5.11.3 Recommendations

- Good studies are needed to address the entity of urethral complications of obstetric VVF.
- Involvement of the urethra in the original fistula may worsen the outcome of the repair and is associated with higher incidence of postoperative stress urinary incontinence. (EL3)
- Treatment of urethrovaginal fistula is always surgical and needs special surgical techniques and tissue interpositioning. (EL3)
- Treatment of stress urinary incontinence following repair of urogenital fistula is more wisely done by autologous pubovaginal slings. (EL4)

5.12 Ureteric Ligation/Injury due to VVF repair

5.12.1 Introduction

Injury to the pelvic ureter is one of the most serious operative complications of gynecologic surgery. VVF repairs lead to 10–15% of ureteric injuries (97). Ureteral injuries can be either expected or unexpected, and they may be the result of carelessness or due to a technically challenging procedure.

The six most common mechanisms of operative ureteral injury are as follows:

- Crushing from misapplication of a clamp
- Ligation with a suture
- Transection (partial or complete)
- Angulation of the ureter with secondary obstruction
- Ischemia from ureteral stripping or electrocoagulation
- Resection of a segment of ureter

Any combination of these injuries may occur (98,99,100).

The ureter injury occurs most commonly in the lower third of its pelvic course and injuries classically occur in one of the four anatomical locations.

- Cardinal ligament where the ureter passes under the uterine vessels
- At or below the infundibulopelvic ligament
- Along the lateral border of uterosacral ligament
- Where the ureter lies in close proximity to the anterior vaginal wall and enters the base of the bladder (101,102,103,104,105,106).

Most studies show the most common site of injury to be lateral to the uterine vessels (106), (106) but Daly *et al.* (97) report this to be at the ovarian fossa. During laparoscopy the ureter is injured most frequently adjacent to the uterosacral ligaments (107).

5.12.2 Classification

According to the Organ Injury Scaling System developed by the Committee of the American Association for the Surgery of Trauma (109), ureteric injuries are classified as follows:

This anatomical classification does not however, appear to have clear prognostic implications.

| | |
|-----------|---|
| Grade I | Hematoma: contusion or hematoma without devascularization |
| Grade II | Laceration: <50% transection |
| Grade III | Laceration: >50% transection |
| Grade IV | Laceration: complete transection with 2 cm of devascularization |
| Grade V | Laceration: avulsion with >2 cm of devascularization |

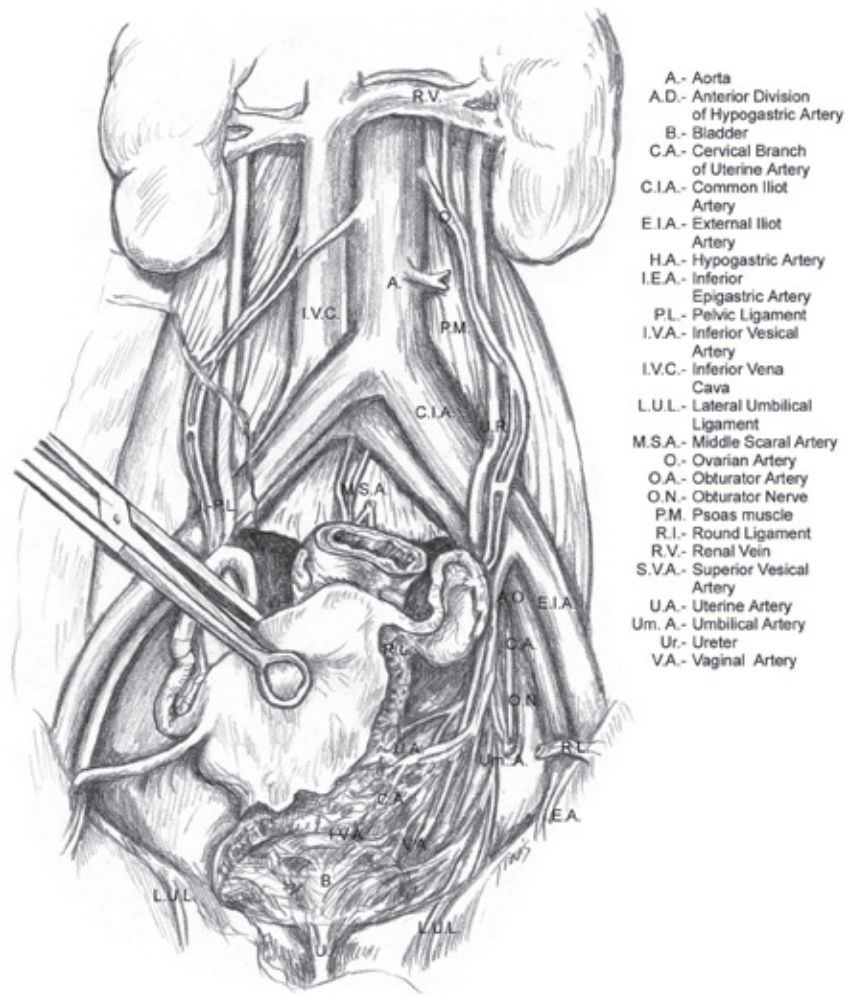
Numerous consequences may occur after ureteral injury, including spontaneous resolution and healing of the injured ureter, hydronephrosis, ureteral necrosis with urinary extravasation, ureteral stricture formation, and uremia (110,111). Inadvertent ligation of the ureter is an example of such an injury. If this injury is noticed in a timely fashion, the suture can be cut off the ureter without significant injury (112,113,114). If the urine in this obstructed system becomes infected, the patient will almost certainly become septic with pyonephrosis (115). The unrecognized ligation of the ureter, produces ureteral wall necrosis due to pressure-induced ischemia leading to urinary extravasation into the periureteral tissues. Urinary ascites may also develop and peritonitis may ensue (116,117). Ischemic strictures of the ureter, leading to obstruction and hydronephrosis of the ipsilateral kidney, are not uncommon (118,119). Uremia results from bilateral ureteral injury or from a unilateral injury occurring in a solitarily functioning kidney (118,119). Presentation of ureteric injury occurring in a solitarily functioning kidney (118,119).

5.12.3 Presentation of ureteric injury

The patient may present with flank pain, prolonged ileus, fever, watery vaginal discharge, or elevated serum creatinine levels. In cases of bilateral ureteral injury, anuria is the first clinical sign (120,121).

FIGURE 7

Relevant anatomy of the ureter, illustrating its course from the renal pelvis to the bladder. Note the ureter's proximity at the pelvic brim to the infundibulopelvic ligament.



5.12.4 Diagnosis

Intraoperative recognition is critical so that it can be repaired and renal functional compromise can be avoided (122,123,124). This enables prompt repair and is associated with decreased morbidity and fewer legal risks (125). In situations where visualisation of the ureters is not feasible, intravenous administration of methylthioninium chloride or indigo carmine (5 ml) is an accurate means of demonstrating ureteric patency (126). The use of intraoperative cystoscopy and telescoping during urogynecology procedures has shown an incidence of urinary tract injury of 2.6–8% (127,128). A decision analysis model shows that routine cystoscopy is cost-effective if the rate of ureteric injury exceeds 1.5% for abdominal hysterectomy or 2% for vaginal hysterectomy or laparoscopically assisted vaginal hysterectomy. Cystoscopy should therefore be considered in complex cases.

Flank pain and fever are the most common symptoms complained postoperatively. Hematuria, a reliable indicator of renal trauma, is absent in approximately 30% of ureteric injuries (129,130). Women may occasionally present with a retroperitoneal urinoma (131).

5.12.5 Prevention

It is recommended that routine identification and dissection of pelvic ureter be performed at the beginning of any difficult pelvic surgery (132,133). Of particular use in laparoscopy are lighted stents, which illuminate and help identify the ureter, thereby reducing the risk of iatrogenic injury (134).

5.12.6 Management

There are major variables guiding a surgeon's approach to the management of ureteric injuries: time of diagnosis, etiology, length and location of the injury, extent of the causative operation and the condition of the woman (135).

Surgical management options for ureteric injury ^(136–138)

- Needle injury - No action unless bleeding or leakage
- Partial transection - Stent placement
- Complete transection (no loss of length)
- 5 cm from vesicoureteric junction - Uretero-neocystostomy
- 5 cm from vesicoureteric junction - Uretero-ureterostomy
- Complete transection (loss of length) - Psoas hitch
- Boari flap with a psoas hitch
- Transureteroureterostomy
- Ureteroileocystostomy
- Ureterocalycostomy
- Renal autotransplantation

Specific procedures and principles ^(139–150)

Ureteroneocystostomy

Injuries to the lower ureter are usually associated with disruption of blood supply from the iliac vessels. Hence, these injuries are best repaired with ureteroneocystostomy.

Vesicopsoas hitch

This is the treatment of choice for lower ureteral injuries that cannot be successfully repaired with ureteroneocystostomy alone. It involves mobilizing the bladder and pulling it superiorly and laterally by fixing it to the psoas tendon with an absorbable suture. This technique can be used to bridge a 6– to 8–cm defect.

Boari bladder flap

For injuries too long to be bridged with the psoas hitch procedure alone, a Boari flap can be created to provide an additional 12–15 cm of length. In this procedure, a pedicle of bladder is swung cephalad and tubularized to bridge the gap to the injured ureter.

Other surgical options

Options for elective repair include autotransplantation or an ileal ureter.

Autotransplantation

This involves relocating the ipsilateral native kidney to the pelvis; the renal artery and vein are then anastomosed to the iliac vessels, and the healthy ureter or renal pelvis is anastomosed to the bladder.

Ileal interposition

This procedure involves the creation of a ureteral conduit from ileum and bridging the gap. Both autotransplantation and ileal conduit are inappropriate in the acute setting.

Urinary diversion

Urinary diversion in the form of a stent and/or nephrostomy tube should be considered, when indicated.

Retrograde ureteral stent placement

An endoscopic approach with retrograde ureteral stent placement may be effective in certain iatrogenic injuries and injuries secondary to external violence

5.13 Neurological Complications of VVF

5.13.1 Discussion

Prolonged obstructed labor results in pressure induced ischemia and necrosis of the vagina, bladder, (occasionally) ureters, urethra and rectum, often provoking profound genitourinary fistula formation. These injuries may be part of a syndrome called the obstetric labour injury complex, which can include damage to the urological, gynecological, gastrointestinal, neurological and musculoskeletal systems (103).

Neurological complications of VVF can involve peripheral (peroneal) or perineal nerves. Peripheral nerve injury is estimated to occur in 5% of women exposed to obstructed labour and VVFs in Sierra Leone. Since most women in Sierra Leone do not deliver in hospitals, urgent medical attention, such as caesarean section, for prolonged obstructed labour is often substantially delayed or completely unavailable (89). This incidence can be underestimated.

In a study in northern Nigeria, when chart of VVF patients were reviewed, only 5.3% of 470 patients were noted to have peroneal nerve injury. In contrast, when patients were asked and examined specifically for symptoms and signs of peroneal nerve injury in prospective manner, 75.9% of them had either symptoms or signs of peroneal nerve injury (153). This may reflect the importance for a focused neurological examination on receiving a patient with VVF since figures of peroneal nerve injury in older reports are much lower (23,154–155). The etiology of this lesion is most probably related to compression of the lumbosacral trunk of the peroneal nerve in the pelvis or due to direct injury of the peroneal nerve due to prolonged squatting and pushing in the 2nd stage of labour (156–157).

Peroneal nerve injury is mostly unilateral and occurs more often on the right side. Nevertheless, it can still occur on the left side and can be bilateral. In the study by Waaldijk and Elkins of 311 patients with peroneal nerve injury, peroneal nerve injury occurred bilaterally in 47 patients, on the right side in 211 patients, and on the left in 146 patients. Most of these injuries resolve spontaneously. Only 13.3% persisted beyond two years after the occurrence of VVF (154).

Neuropathy associated with VVF can also involve the perineum. In a study, 68.18% of fistula patients presented with a clinical neuropathy in the perineum. When these patients undergone electromyography, all fistula patients with VVF in this study showed a degree of denervation. In contrast, there was no detectable lesion either clinically or by electromyography.

The severity of this lesion ranged from moderate (36.37%) to severe (63.63%). The severity of the lesion is related to age of presentation since it is more severe in younger age. Furthermore, it is more severe in primiparous ladies. Interestingly, it appears from that study that the success of repair is affected by the severity of the lesion, since severely denervated cases are usually associated with repair failure or at least persistent vesicosphincteric dysfunction (153).

Complex neuropathic bladder disorder can occur as a result of obstetric VVF. This has been discussed somewhere else in this chapter.

5.14 Infertility as a Complication of VVF

Vesicouterine fistulas can present in different ways, depending on their location, size, and the degree of patency of the endocervical canal. The least troublesome vesicouterine fistulas do not result in incontinence, but are characterized by the absence of vaginal menstruation in the presence of cyclic hematuria (“menouria” or “Youssef’s syndrome”), whereby the menstrual flow exits exclusively through the urinary tract (159–161).

Other vesicouterine fistulas may be associated with various combinations of altered menstruation and either periodic or continuous incontinence. The finding most characteristic of an uterovesical fistula is demonstrable loss of urine through the cervix (a finding that also occurs with vesicocervical fistulas).

Many patients sustain severe cervical damage as well as vaginal injury during the course of obstructed labour. It is rare to see a completely normal cervix when examining a fistula patient. In the worst cases, prolonged obstructed labour may result in complete cervical destruction, leaving the patient with no identifiable cervical tissue at all.

Unfortunately, detailed descriptions of the condition of the cervix have not been included in the case series of fistulas published to date. Since cervical competence is such an important factor in future reproductive performance, this is yet another clinical area that demands further study. Other studies have shown amenorrhea rates from 25% to 44% (162–164).

Many of these patients undoubtedly have hypothalamic or pituitary dysfunction (165). A follow-up study by Browning *et al.* showed that while the amenorrhea rate was 58% pre-operatively, this rate improved to 29% at six months after surgery, suggesting a recovery of ovulation in a proportion of operated women (166). While the high incidence of amenorrhea in VVF patients is widely recognized, only one unpublished study has been done to date looking specifically at uterine pathology in the VVF population.

Dosu Ojengbede of the University of Ibadan (personal communication) performed hysteroscopy on fistula patients in Nigeria and found that intrauterine scarring and Asherman’s syndrome were common in these women. The combination of widespread amenorrhea, vaginal scarring, and cervical destruction leads to a tremendous problem of secondary infertility among these patients. To date, there have been no serious scientific efforts to explore treatment of cervical and uterine damage in VVF patients.

Subsequent reproductive performance of women who have had an obstetric VVF has been analyzed in a few articles (164,166,167). Emembolu analyzed the subsequent reproductive performance of 155 fistula patients delivered at Ahmadu Bello University Teaching Hospital in Zaria, Nigeria, between January 1986 and December, 1990 (168). This series included pregnancies in 75 women who became pregnant after successful fistula closure and 80 women who became pregnant while still afflicted with an unrepaired fistula that had occurred in a previous pregnancy.

In women with pre-existing, unrepaired fistulas who became pregnant but who did not register for prenatal care in the subsequent pregnancy, maternal mortality and morbidity in those pregnancies was high, reflecting continuation of the conditions that led to fistula formation in the first place (169).

The commonest maternal morbidity, excluding recurrence of VVFs, was haemorrhage requiring blood transfusion in 35 patients (27.3%). Others included ruptured uterus in three unbooked patients whose fistula had not been repaired, bladder injury at caesarean section in 1.6% and acute renal failure in 0.8%.

Maternal complications occurred more frequently in the patients whose fistula had not been repaired and who were also unbooked. The largest series is that of Aimakhu, who analyzed subsequent reproductive performance in 246 women who underwent successful fistula closure at University College Hospital in Ibadan, Nigeria, between 1957 and 1966 (163). Only 48 patients became pregnant following fistula repair with a total of 65 pregnancies.

All but six of these were managed at University College Hospital. Five patients aborted prior to the 16th week of gestation, leaving only 60 viable pregnancies. The plan was to perform elective caesarean section on all patients who became pregnant after fistula repair, but only 49 caesarean operations were carried out. The results of the vaginal deliveries were not encouraging.

Patients who underwent caesarean delivery fared better. There were 49 babies delivered and 47 survived. There was no recurrent fistula among women previously repaired who became pregnant and had a subsequent caesarean section. There was one maternal death from pulmonary embolism in a woman who underwent an emergency delivery at 32 weeks gestation due to a prolapsed fetal umbilical cord.

5.15 Psychological Complications

5.15.1 Introduction

Women with urinary or fecal incontinence show depression, anxiety, and abnormal levels of situational life stresses. It is likely that psychological changes are related to the symptom and related disability and distress than to specific urogynecologic conditions. Feeling of insecurity, anger, apathy, dependence, guilt, indignity, feeling of abandonment, shame, embarrassment, depression and denial are also common. Women feel loss of self-confidence and self-esteem.

In addition to these physical problems, fistulas cause acute social problems. As a result of the continuous leakage of urine and feces into the vagina, affected women often have an offensive odour, leading them to be ostracized by their husbands, families, and community. For example, families do not want fistula survivors preparing food or participating in family events. Commuting in public

transport and engaging in social activities such as weddings and naming ceremonies becomes difficult. Women tend to get socially disengaged and socially isolated. Psychological and functional decline prevails and potential for institutionalization occurs.

5.15.2 Psychosocial impact

Wyman *et al* (1990) examined epidemiologic and clinical studies addressing the psychosocial impact of urinary incontinence on community-dwelling women (184). They noted wide variations among studies regarding patient populations surveyed, methods of evaluation, and definitions used. Reports of interference with social activities ranged from 8% to 52%. Areas affected included social, domestic, physical, occupational, and leisure activities. Sufferers may give up or restrict certain household chores, church/temple/holy-places attendance, shopping, travelling, vacations, physical recreation, entertainment events outside the home, and hobbies. They may avoid activities outside the home if they are unsure of restroom locations. Some incontinent women become increasingly isolated as they limit social activities and social contacts. Even incontinent home-bound women, have significantly fewer social interactions, particularly with family members.

5.15.3 Family relationship

Urinary and fecal incontinence can lead to such disability and dependency that family or home caregivers have difficulty coping and responding to increased demands. Incontinence may be the last straw in a family's attempts to care for a disabled woman. It is a major factor leading to institutionalization and may be a secondary reason for many more. Economic worries for the families are enormous, caregiver burden and emotional stress on the families is phenomenal (170). Health deterioration of primary caregiver and impaired interpersonal relationships are common. Potential for abuse or neglect is real. Decision to institutionalize and delayed discharge from institutional care are frequently seen. Negative feelings and behaviours toward patients with urinary and fecal incontinence sometimes are noticed. Patients are seen as extra care responsibilities and "burn-out" syndrome is prevalent among the healthcare providers of the women with urinary and fecal incontinence. Reaction formation such as overindulgence, excessive permissiveness and excessive caring is not uncommon.

5.15.4 Spousal relationship

Spousal relationships appear to be most impaired, perhaps because of an additional adverse effect on sexual relationships. The close anatomic proximity of the bladder, urethra, and rectum with the vagina allows for an association between lower urinary tract or anorectal dysfunction and sexual difficulties. The effects can be bidirectional; sexual activity can cause or aggravate bladder or anorectal problems, and bladder or anorectal problems can lead to sexual dysfunction. The association between urologic symptoms and sexual problems may occur in several ways. Urinary symptoms may be a direct cause of sexual difficulties, where none previously existed. Alternatively, urinary symptoms may be used (consciously or unconsciously) as an excuse to avoid sexual contact in the presence of a pre-existing but unacknowledged sexual problem. Declining general health of the woman may affect sexual activity. Thus, many complex factors affect the quality of sexual function (171).

5.15.5 Sexual health and consequences

Additionally, vaginal injuries can result in a woman's inability to perform her expected duties, from manual labour to having sexual intercourse with her husband (5). In societies in which a woman's worth is dependent on fulfilling her marital (sexual) duties, this situation is devastating (172). If the fistulas are not repaired, their husbands may divorce the women. In Niger, fistula accounts for 63.3% of all divorces (173). According to an Ethiopian study of previously married women with fistula repairs (n=78), all the women's husbands either divorced them (n=59) or abandoned them (n=19) (174). Kelly reported that husbands had rejected more than 50% of patients at the Hamlin Addis Ababa Fistula Hospital (175). In a Nigerian study of 31 fistula patients, the divorce rate, even after repair, was 55%; 87% of these women had a stillbirth (176). Some leave their families to roam in the cities where they are not known as the outlook for them remain bleak in the community. Given that fetal death often occurs during the obstructed labour that caused the fistula, the subsequent amenorrhea, which can often be permanent and even after repair lasts for up to two years (59), further compounds the woman's childless state and cultural valuelessness.

5.15.6 Management

It is widely accepted that urinary and fecal incontinence is under-recognized and undertreated. Fewer than half of people with incontinence in the community consult their healthcare providers about the problem. The reasons for this include embarrassment, availability of absorbent products, low expectations of benefit from treatment, and lack of information regarding options for treatment.

The sufferer has various stresses including physical, psychological and socio-economic. Many of these women feel intimidated to attend a hospital and are also vulnerable and this leads to psychological trauma.

Many studies suggest that psychological factors associated with urinary or fecal incontinence can be modified with therapy (177). Interventions to address the problem of VVF have to be one with holistic approach to include treatment, rehabilitation and follow up in the community (178).

Ideally, interventions should be done with counselling from the time the sufferer comes to seek help, through to when she returns to her community. The counselling will form part of a whole package of rehabilitation which ideally should start with the treatment but not end with it. Only by this approach can bring complete healing for those suffering with VVF.

Contributory factors for psychological trauma during VVF treatment (179–181)

- Most of the women are malnourished and good nutrition is not affordable
- They suffer from untreated infections
- The need for multiple surgeries – no funding
- Understaffed nursing care team
- Poor rehabilitation centre care
- Husbands not involved in counselling and have no sensitization
- Husband's insistence on sexual activity and women fear refusal due to Islamic faith.

Sexual function may be positively or negatively affected by the surgical treatment of urinary incontinence. Deterioration is many times seen after extensive pelvic floor repair.

- Pregnancy soon after surgery - repair disintegrates
- Subsequent childbirth, if not properly supervised, may result in another fistula

Steps to prevent psychological trauma (180,181)

1. Counseling (peer and professional), surgical treatment and appropriate pre- and post-surgery nursing care.
2. Residential rehabilitation – where activities are coordinated and managed, to educate and train women on income-generating skills
3. Physical and psychological rehabilitation at the centre and subsequent reintegration of women into their communities, with 12 months follow-up and monitoring of reassimilation
4. This will ensure they create links with other women like themselves in an atmosphere of support and learning. The issues of the VVF are put in a structure of health, reproductive and sexual health and rights so that they understand what and how the VVF occurred and what to do in order to prevent it from happening again.

Assessment of psychological well-being

Increased risk of pelvic dysfunction, stress incontinence, anal incontinence, dyspareunia and vulval problems following the repair are increased in incidence and duration. The prevalence and severity, including any related psychosocial ill-health in this population, needs further definition. Impaired social functioning is assessed by analyzing any delay resulting from its interference with usual postpartum social activities (182).

The grading of the severity of psychosocial morbidity makes it easier to quantify, and its feasibility for assessing obstetric outcomes should be evaluated prospectively (183).

1. Function resumed 0–12 weeks postpartum (normal range)
2. Function resumed 13–24 weeks postpartum (mild impairment)
3. Function resumed 25–36 weeks postpartum (moderate impairment)
4. Function resumed after 37 weeks postpartum (severe impairment)

5.15.7 Conclusions

In the presence of stress incontinence and dyspareunia, a biopsychosocial morbidity could be severe.

Pelvic dysfunction can contribute to relationship problems with their infant or with their partner.

The approach for assessing the overall predicted morbidity and perceived maternal needs associated with pelvic dysfunction could have a role in the management of these patients and development of relevant support services.

At least for the short term, quality of life and other second-order benefits must be considered if continence rehabilitation is to be cost-effective.

Awareness about VVF as a treatable condition should be encouraged in the community.

It is very helpful in improving the status of women in the society by encouraging them to learn about the appropriate care.

Maternal health interventions are among the most cost-effective investments in health. Good maternal health services can strengthen the entire health system.

The importance of skilled care during pregnancy and childbirth is vital and essential.

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C6

Social Reintegration of Obstetric Fistula Women

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6.1 Identification and Assessment of Evidence

This chapter was developed in accordance with standard methodology for ICUD consultations.

For the purposes of this chapter, articles and programmes related to the topics “social reintegration” and “rehabilitation in obstetric fistula management” were reviewed. Relevant published evidence was identified by systematic search strategies of databases via the Ovid platform: Medline (1966 onwards), Embase (1980 onwards), Cumulative Index to Nursing and Allied Health Literature (CINAHL; 1982 onwards), and PsycINFO (1967 onwards) including in-process and other non-indexed citations, using the terms “social reintegration”, “rehabilitation” and “obstetric fistula”. The reference lists in these articles were checked against subsequent searches to identify relevant evidence. There was also a systematic attempt to search grey literature (conferences, abstracts, theses and unpublished trials) and hand searching of journals not indexed on the databases. Additionally, stakeholder organizations were invited to submit evidence for consideration provided it was relevant to the topics included in the scope, and of equivalent or better quality than evidence identified by the search strategies. Finally, a literature review was also conducted within the broader context of social reintegration and rehabilitation in other indirectly related fields.

The date of the last search was June 2011. Selection of articles for analysis and review was then made, based on the topics: social reintegration and rehabilitation in obstetric fistula management. Articles were shared with the panel and rated as to their Level of Evidence (LE) based upon the criteria of the Oxford Centre for Evidence-Based Medicine. Subsequent to this review, recommendations are made by consensus for the issue of social reintegration of obstetric fistula survivors, with the appropriate grades of recommendation based upon the level of evidence.

6.2 Why Social Reintegration?

There has been a greater focus on the reintegration into family and communities of women and girls with obstetric fistula in recent times (2-8). The impact of fistula is seen as much wider than “just a hole in the bladder/rectum,” (9) but an immense psychosocial-economic vulnerability; with women who are usually of low socioeconomic status and from rural areas at risk of being left without traditional societal roles and security; including conjugal and family relations, children, community acceptance, and economic opportunities driving them into seclusion, psychological trauma and poverty (10-22); and without support systems or persons to help them cope with their long-term physical, psychological, and socio-economic needs in their communities.

New arrival at the Babbar Ruga fistula hospital, Northern Nigeria.



It is these reasons, and the fact that the root causes of the obstetric fistula, such as abject poverty, gender discrimination, lack of education for women, and deeply embedded cultural and social values are further magnified by the condition, that have caused social reintegration programmes to be established over the years (23). Women who have been repaired were said to be usually discharged too quickly from the hospital and, in the absence of proper aftercare, are thrown back into the same cycle of exclusion, undernourishment, illiteracy and another pregnancy, without having fully recovered from their operation. Furthermore, they may contract a myriad of significant physical-social complications including recurrent fistulas, ongoing incontinence and sexual and reproductive dysfunction that are not completely alleviated by repairing the fistula alone (7,24-26). Accordingly, these programmes and many others are beginning to call for a comprehensive approach to fistula that moves beyond just the physical or functional restoration of continence but which also provides women with the support they need to respond to the multiple and often interlocking physical, social and psychological problems that may prevent them from dealing with the realities of life after surgery and regaining self-sufficient societal roles (1,3,9,10,13,25,27-29).

However, in general the social reintegration of fistula patients into their community is still weak on the ground. A midterm thematic evaluation of the United Nations Population Fund (UNFPA) national fistula programmes in 2009 found it to be the least prioritized intervention of the Campaign to End Fistula (30). Field missions conducted in Bangladesh, Nigeria, the Democratic Republic of the Congo and Niger, and desk reviews of national fistula programmes in Kenya, Pakistan, Sudan and

Tanzania found social rehabilitation and psychological support services for fistula survivors to be a weak link in the fistula management process. This is despite the attention being paid to reintegration in more than 25% of “Campaign to End Fistula” countries.

This presents a challenge then in ascertaining best practice; another being the marked deficiency of published systematic or randomized trial data on the effectiveness of already implemented reintegration strategies, or on clinical and operational research that shows the impact of reintegration services on affected women’s quality of life and social status. The vast majority of studies simply mentioned reintegration within the context of small case series with a wide range of approaches. In addition, little follow-up has been done regarding services for support and reintegration of women with women who have undergone repair (31). A pertinent quote from the fistula network site being “Reintegration is an area of much concern but little information that is not anecdotal” (32).

In line with this lack of robust evidence and the increasing call for reintegration to be based on the needs and wishes of women, as they are best served to identify services best suited to their particular needs (33,34), much work has gone into identifying reports which focus on women’s accounts and perspectives of living with fistula. These reports also come from the perspectives of those who work in the social reintegration field. This work includes secondary data on fistula, such as reports on causes and consequence, policy guidelines, and strategy papers. The aim is to focus on defining social reintegration, what facilitates it, and how to respond to the challenges it raises in the context of women’s individual needs. Though the majority of studies/reports involved use small numbers and anecdotes, they serve to provide data that is rich as they are qualitative in nature such that “one can learn a great deal about issues of central importance to the purpose of the inquiry” of social reintegration (35).

6.3 What is Social Reintegration?

“The strategy is based on the principle of addressing the survivor’s needs and wishes”(33).

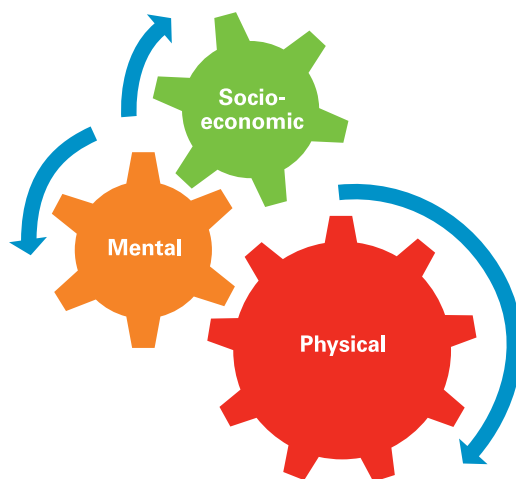
The term “social” in social reintegration is taken literally, as many see it as predominantly a social tool and something for social workers/NGOs to take care of, as determined from a survey of fistula surgeons (36). Additionally, the country questionnaires, sent out during the midterm evaluation of the Campaign to End Fistula, found that most respondents pointed to the fact that social reintegration services are best provided by involving (community-based) NGOs (37). Some replied that advocacy by NGOs was also better for obtaining acceptance of women by their families and communities. However, in other fields where the term social reintegration is commonly used, such as psychiatry, women prisoners, and ex-combatants etc. (38,39), it is actually about more than just solitary efforts by a social worker, but rather, as enabling the autonomy necessary for a person to define their own social participation, including favourable health, family environment and livelihood support. A broader definition encompasses recovery and rehabilitation (40); where recovery is seen as the process by which a person recovers from the stigma people have incorporated into their being. Rehabilitation and reintegration are seen as part of the same process of interventions that practitioners use to facilitate recovery. A rehabilitation approach consist of interventions, regardless of

who performs them, that focuses on the individual by helping them define what they want, and to acquire the abilities and resources they need to succeed. On the other hand, reintegration is part of the process that uses these resources so that people can assimilate them into their daily life, as would be appropriate for anyone in a peer group the person should wish to be part of (40).

The economic, psychological, and social aspects of rehabilitation and reintegration are also said to be inextricably linked (39). One's social role is often seen as related to economic input and income, whilst psychosocial problems are often cited as interfering with the ability to engage in socio-economic opportunities. As such, this implies that the word "social" does not just mean social tools or interventions, but anything which can raise the level of social functioning so as to mitigate the background of poverty and the negative impacts of exclusion, so that one can become part of the social, economic and cultural fabric of the original community (or even a different community).

The same rationale is thought to apply to the obstetric fistula, although there is no formal definition of it within this context, and there is a lack of clarity about exactly what reintegration means and the types of interventions and stakeholders that can best facilitate it (30). A review of the literature and programmes show that the term is a broad constellation of different interpretations and approaches by caregivers, ranging from clinicians to social workers. But as indicated by the complex nature of the psychosocial and economic problems detailed above, social reintegration in the fistula arena involves a comprehensive intervention encompassing various realms (**Figure 1**).

FIGURE 1
Drivers of social reintegration: reducing the fistula occurrence-recurrence cycle



An appropriate intervention is seen as one that takes care of the physical, mental, social, and economic damage that has been commonly inflicted on girls and women with fistula that mitigates the poverty of women and the negative impacts of any form of exclusion (23). The objectives would be to improve their ability to live productively and with the same opportunities as their neighbours by developing the abilities needed for adequate functioning in the community. Some go further to define it as taking place in communities and that "there will be a successful social reintegration for the woman only if her local community recognizes that she has recovered her lost or restricted rights and accepts her as a full member of the community" (41).

It is also said that to fully reintegrate operated women into their community, they should become significantly less susceptible to a re-occurrence of the condition by the implementation of preventive initiatives that will reduce the overall vulnerability of women, and subsequently the entire population, to the development of fistula.

The lack of a universal definition of “social reintegration” has been highlighted by reports which conclude that reintegration is multifaceted, requiring interrelated components: physical health, mental health, and social and economic well-being (42-43). However, implicit in these and other reports (11) is that reintegration strategies should be defined by the expectations of women with fistula themselves; by being mindful of their voices and priorities so as to provide meaningful services. Especially as it has been well recognized that fistula consequences can vary dramatically from country to country and region to region such that a “one size fits all” approach cannot be adopted (2,6,43,44). A study conducted looking at the methods used by social workers to help women with fistula concluded that understanding the problem from the perspective of the women survivors enhances the treatment and prevention work that is being conducted (34).

6.3.1 Needs of women in the social reintegration process

Several interventions are frequently cited as playing a part in helping women to get their lives moving again and reintegrated back into their communities (43). These were tabled by the indicators and research group of the IOFWG (42) (**Table 1**) and subsequently reviewed at a fistula partners meeting, as indicators that define the services needed in reintegration (45). These indicators of physical and mental health, as well as social and economic well-being, acknowledge the multifaceted nature of reintegration and include efforts with women, both as individuals and within the community.

Programmatic evidence and the literature reveal that by far, the physical realm plays the biggest part in the reintegration process as depicted in **Figure 1**. However, in reality there is considerable overlap between each realm, which can be thought of as interlocking and serving to drive success in each other. For ease of explanation, each realm can be thought of as a matrix (**Table 2**) and is discussed here separately.

TABLE 1 Objectives and Indicators of Social Reintegration

(Meeting Report: International Obstetric Fistula Working Group, 11-13 October, 2006. Geneva, Switzerland)

| Objectives | Draft Indicators |
|--|---|
| 1. At the individual level | |
| Success of repair procedure | <ul style="list-style-type: none"> Proportion of women who access treatment (regardless of outcome) |
| Improved physical health including: <ul style="list-style-type: none"> continence; return to fertility and/or sexual life as desired by the woman; improved nutrition | <ul style="list-style-type: none"> Number/proportion of women receiving counselling services Number/proportion of women accessing family planning Number/proportion of women achieving a desired live birth |
| Improved mental health including: <ul style="list-style-type: none"> increased self-esteem; peer support | <ul style="list-style-type: none"> Number/proportion of women receiving counselling services on mental health issues Number/proportion of women experiencing stigma from their community |
| Increased social connection including: <ul style="list-style-type: none"> reduced stigma; reintegration into family as desired by the woman; increased social support; participation in social or religious life as desired | <ul style="list-style-type: none"> Number/proportion of women receiving counselling services on social issues Proportion of community members with positive attitudes towards women with fistula Proportion of male partners that facilitate access to prevention and treatment services Proportion of women who can maintain positive household and social relations |
| Improved economic well-being including: <ul style="list-style-type: none"> higher income level; engagement in economic activities; family economic support; capacity to support others | <ul style="list-style-type: none"> Number/proportion of women receiving counselling services on economic issues Number/proportion of women, who regain or improve their prior economic status |
| 2. At the community level | |
| <ul style="list-style-type: none"> Proportion of women treated that are referred for reintegration services Number and distribution of community-based reintegration services Proportion of community members with knowledge about fistula prevention, treatment and rehabilitation Percentage of community members with positive attitudes towards women with fistula Proportion of male partners, who facilitate women's access to prevention and fistula treatment services Proportion of family members, who facilitate women's access to prevention and fistula treatment services. | |

Programmatic evidence and the literature reveal that by far, the physical realm plays the biggest part in the reintegration process as depicted in **Figure 1**. However, in reality there is considerable overlap between each realm, which can be thought of as interlocking and serving to drive success in each other. For ease of explanation, each realm can be thought of as a matrix (**Table 2**) and are discussed here separately.

TABLE 2 Social Reintegration Matrix (Esegbona/ Mohammed)

| Element | Level | | |
|--|---|---|--|
| | Individual/ Facility | Community | Political |
| <p>Physical</p> <ul style="list-style-type: none"> Improved physical health (e.g., improved continence and return to desired fertility/sexual life) | <ul style="list-style-type: none"> Rehabilitation A timely repair A successful repair | <ul style="list-style-type: none"> Outreach Health education Follow-up | <ul style="list-style-type: none"> Allocate funds for treatment |
| <p>Psychological</p> <ul style="list-style-type: none"> Improved mental health (e.g., self-esteem) Improved knowledge about fistula prevention, treatment and rehabilitation | <ul style="list-style-type: none"> Counselling on clinical, psychological, social and economic issues. Peer support | <ul style="list-style-type: none"> Advocacy and sensitization Follow-up | <ul style="list-style-type: none"> Raise awareness on issues of stigmatization |
| <p>Socio-economic</p> <ul style="list-style-type: none"> Improved social connection (e.g., reduced stigma, reintegration into family as desired by the woman, participation in social or religious life as desired) Improved economic well-being including: higher income level; engagement in economic activities; family economic support; capacity to support others | <ul style="list-style-type: none"> Designated space to recuperate Vocational skills training | <ul style="list-style-type: none"> Microcredit or finance Community-based reintegration services Immersion follow-up | <ul style="list-style-type: none"> Linkage with ongoing national poverty alleviation programmes |

Improved physical health

“The continuous leakage of urine and offensive smell are unacceptable in any society. Therefore, fistula management has to start the moment the leaking of urine becomes manifest to prevent this social disaster.”(46)

Surgery and continence

The capability approaches of Sen and Nussbaum suggests that poverty is not just related to income-deprivation, but the individual capability for health. It is bodily health and integrity that enables the capability of full functioning in social life and the justice of being able to enjoy “valuable doings and beings”(47-48). Thus, restoring the physical ability of women with fistula can be seen as a leap towards reclaiming their proper social order (augmented by concomitant psychosocial therapies) (49).

The contribution of the repair procedure to the social reintegration process is frequently underestimated; with many (52 out of 60 doctors) seeing social reintegration as social work and not anything to do with them and surgery (36). However, much of the evidence from studies looking at the lives of women living with fistula point to the fact that it is the continuing wetness, malodour and discomfort from urine-induced genital sores that are causing social outcasts (5-6,8,11,15,50-51). It follows

that curing the leakage would go a long way to easing a woman's reintegration back into society as it makes her continent and able to physically, psychologically and socially resume a full and productive life that allows her to interact freely with family and community, and support herself. This is borne out in personal communications with reintegration programmes (23,41), and anecdotal reports (44) cited by others. The common thread being that almost all a woman wants is to be cured of her incontinence, and if she is, her mental health improves, and she can get back to her normal living arrangements and back to her normal work. In other words, she reintegrates by herself and she will then only come back for further help if she is still leaking post-repair, in a manner which is incompatible with maintaining social relationships.

Reports also talk indirectly of social reintegration, post-fistula repair, by describing the increasing number of women coming back for caesareans or the ones that want care for their gynatresia (vaginal stenosis), or dyspareunia (painful intercourse); the assumption being that they must be back with their husbands or have married again (equivalent to increased social functioning) if they are concerned about intercourse or are pregnant! (44,46)

This ties in with studies which allude to the importance of surgery to women in ensuring that successful reintegration happens. For instance, in a study at L'Hôpital Saint Jean de Dieu in Tanguieta, Benin, in which 37 fistula patients underwent structured interviews about reintegration, it was found that 49% of women requested no further reintegration assistance aside from surgery (52). In addition, a meta-analysis of two of the major consequences of having a fistula (divorce/separation and perinatal child loss) suggested that surgical treatment usually closes the fistula and improves the physical and mental health of affected women (13).

Similarly, a study done to understand the dimensions of fistula and its related social vulnerability in Tanzania found that life improved dramatically for the majority (more than 50%) of the 61 girls and women after their fistula repair (11). They reported being able to return to their normal lives and interact freely with family, friends, and the community. The majority of the women who had successful repair also mentioned being able to support themselves and their families financially and being able to perform domestic chores – such as fetching wood and water, farming and cooking.

In addition, structured questionnaires administered to women living with obstetric fistula in Kenya found that almost all of the 40 women who received surgery for their fistula (97%) said their family and community were very welcoming when they returned home (n=39) (53). The majority were able to socialize normally and carry out daily activities. In addition, many (63%) were still with their original husbands and around half (53%) had resumed sexual relations. In DR Congo, most of the women interviewed expressed joy in recovering their health and “value” as women, indicating that the change in their condition would allow them to regain their position in their respective communities and live like other people (50). Aspirations involved working and earning money, and for those women not married, establishing a long-term relationship with a man. In addition, during the follow-up visits to their communities, most of the women with fistula were not at home when the research

teams arrived. But were attending funerals or wedding ceremonies, and a few were found working in their farms, an indication of how they had overcome the stigma and isolation they faced when they had fistula.

Overjoyed after repair at Babbar Ruga Fistula hospital, Katsina, Nigeria.
(Courtesy Gloria Esegbona)



Happy repaired women and girls socializing in the Kwalli rehabilitation centre Kano
(Courtesy Musa Isa)



Similar findings were found in a longer follow-up study to assess the urinary and reproductive health and quality of life following surgical repair of obstetric fistula in rural Western Ethiopia (26). Thirty-eight out of 44 women (86%) who had undergone fistula repair were identified in their community. Community-based structured interviews at 14–28 months following fistula repair, addressing urinary health, reproductive health and quality of life found that surgery improved the quality of life, and facilitated social reintegration to a level comparable to that experienced before fistula development, for both women who were dry and those with residual incontinence in the form of stress/urgency incontinence ($P=0.001$). For women who were still suffering from fistula, no change was seen ($P=0.1$).

A study which involved 61 Tanzanian women with obstetric fistula and members of their families found that majority of the women were able to renew family and community relationships following successful repairs. Women reported being no longer isolated but able to interact freely with their families and communities, and take active roles in economic activities (11).

Similar to these findings, a study explored the barriers and facilitating factors that women experience when reintegrating into society after treatment of an obstetric fistula in rural Tanzania (55). A total of 71 women were interviewed in the Mwanza region in three groups. Group 1 were affected women who had already received treatment and returned to their communities (n=25). Group 2 were non-affected women matched by age and socioeconomic circumstances to the women in Group 1 (n=25), whilst Group 3 were affected women awaiting surgery or recovering in the fistula ward post-surgery (n=21).

When the perceived quality of life (PQoL) was compared between groups, a dramatic improvement over time in PQoL was seen after repair, with the average PQoL score lowest during the period when women were living with a fistula (Group 3), and steadily increasing over time after surgical repair. As most of the women in Group 3 had developed a fistula more recently than those in Group 1, the authors stated that “the decrease in PQoL for Group 3 confirms the immediate negative impact of a fistula on a woman’s quality of life”. And by one year post-repair, over two-thirds (68%) of the women, who perceived themselves healed or mostly healed, reported that, over time, they were able to resume many of the social and economic activities they engaged in, prior to the development of a fistula, especially those with family to support them.

This study also suggests that access to quick repair services improved women’s ability to successfully reintegrate into society. The average length of time between a fistula occurrence and repair in Group 3 was 1.2 years, with a range of two weeks to 10 years living with a fistula; whereas Group 1 lived with a fistula on average seven years, ranging from two months to over 20 years. In contrast to the reports of the women in Group 1, only one woman out of the 21 in Group 3 experienced community mistreatment while living with an obstetric fistula. Five were referred directly after their deliveries and never interacted with community members when they were experiencing symptoms such as incontinence. Five were told to go home for three months (one said this was to heal from a caesarean section) and then to return to the hospital for treatment. The other 11 women in group 3 reported that neighbours and family, “just encouraged [her] to get treatment at the hospital”. The average PQoL for Group 3 dropped from 7.55 out of 10 for the time interval before a fistula development to 3.44 (SD=2.10) for the time period while living with a fistula. In contrast, the average PQoL of women in Group 1 while living with a fistula was 1.81 (SD=1.63), and of the women who developed a fistula in the year 1999 or later (n=11), none were “shunned” by their communities, few were divorced by their husbands, and all received treatment within one year.

This finding of less ostracism and fewer instances of divorce when women were repaired soon after developing a fistula reflects similar findings from earlier research in the study area (56) 56 and other countries (26). The reason given for this, and cited in other papers, is that women who have lived with fistula for a relatively short time, before a successful repair, are more easily reintegrated into their community as they are never away from their communities long enough to be perceived as outcasts (2,31). There is also the fact that there is now a generational difference in the awareness of fistula in that the present generation of women with fistula has faster access to better treatment services than was the case for previous cohorts (55).

It has been noted that in order to prevent discrimination and exclusion from the community, no more than six months should pass from the onset of the obstetric fistula until a woman is repaired (37). One author specifically stating that women with a fistula duration of 3 to 75 days, after delivery, should be treated immediately on presentation, by catheter and/or early surgical closure, to prevent them from becoming an outcast (46).

The practice of waiting two to three months after the fistula has occurred, to give the tissues time to heal before attempting repair (4), is seen as the first step in the direction of the woman becoming an outcast with progressive downgrading medically, socially, and mentally. This situation can have significant negative consequences for social reintegration, as women who frequently remain away from their marital homes become perceived as outcasts of the family and society. For instance, some customs in Northern Nigeria expect a woman to deliver her first baby in her parent's home and stay there for several months to recuperate (41). Hence, early closure minimizes the length of time she is seen as abnormal, or an outcast by her husband and community, as she never interacts with community members when experiencing symptoms such as incontinence. Studies suggest that this keeps the devastating social consequences, such as abandonment or divorce, to a minimum (57).

This ties in with reports of women gradually becoming outcast when it becomes obvious that their fistula condition is chronic (58). In one study, a woman described how her husband visited her every day while she was staying at her parent's house to have the baby. However, once she developed a fistula and was told by the doctors to wait for three months for treatment, he stopped visiting (59). This unnecessary turning of an acute condition, that can be entirely prevented through adequate access to health care, into a chronic condition (51) has been described in other studies (15).

A policy of early closure has now been adopted by several dedicated reintegration projects – such as The Foundation for Women's Health, Research and Development (FORWARD) Nigeria (23) and Delta Survie in Mali (60) – where it is no longer the policy to make women wait: surgical fistula closure is seen as the priority.

Ultimately these studies also point towards the impact of the quality of repair on a woman's social reintegration. This repair is dependent on the expertise of the surgeon and the facilities in which the patient will be operated. Additionally, it is known that the first repair affords the best chance of continence (61,62) When a repair fails, a fistula with a graver prognosis is created, with success rates as low as 66% (63). Women who cannot be repaired then face reintegration challenges.

Biosocial outcomes

“The physical pain is one thing, but then they have also lost their ability to work, to have pain-free sexual relations.”(60)

According to Coetzee and Lithgow, a cure following fistula surgery occurs only when the woman is not incontinent of urine, is able to have coitus without dyspareunia, and is able to bear children (64). In most rural societies where fistulas are prevalent, a woman's social and economic life is defined in terms of sexuality, fertility and the childbearing that results (4,15,19,65). This is especially the case

as the index of pregnancy resulting in their fistula is usually their first and has resulted in stillbirth in over 90% of cases. The resultant childlessness was found to have a major social impact, even if a woman is successfully repaired, due to divorce, stigmatization and psychological stress (3,5,50,59).

The result of one study reported that the wish of many women was to have a husband, as with marriage, the childbearing would follow, giving them status as women and confirming their recovery (50). In another, 32% of the women stated that they desired more children (55). It is also relevant to note that in the same study, none of the women with three or more children before developing a fistula were divorced by their husbands. This highlights the importance of childbearing to women's social status in the study setting. Another study found that many women experienced the fistula as a direct assault on their ability to fulfill social expectations of them as women, wives and mothers. Women identified continued participation in marriage, community and childbearing as central concerns (66). It is reasonable to expect therefore, that an overwhelming proportion of women will want to get pregnant soon, although some noted that this desire is only present if a woman is continent. If she is still leaking, then her only concern is how to get well first (49).

However, far reaching biosocial implications, such as the inability for a woman to satisfy their husband's sexual needs, may contribute towards this childlessness and ultimately their reintegration.

A number of studies point to the problems women may face reintegrating into their local communities because of vaginal injuries that make intercourse painful, unpleasant or impossible such that their marriages are affected. For instance, in Ethiopia when the sexual life of the women was inquired about in in-depth interviews, some stated that their sexual life was the major reason why they were separated from their husbands (59). Out of 30 women, 29 stopped sexual relations after the fistula occurred and moved into their parent's house until they recovered. The reasons given were the trickle of urine and/or feces, the smell, or the genital sores, which made it unpleasant and painful, and lowered their self-esteem.

A successful repair would logically be thought as a means to circumvent these problems. However, studies have shown that the nature of the fistula or even the repair itself can affect reproductive performance. For instance, in one study in which a review was conducted of the existing literature and of expert recommendations, it was noted that closing the anatomical fistula was not always sufficient; with approximately 10% of women found to have gynatresia (vaginal blockage or stenosis) after the first repair. It concluded that treatment paradigms should shift toward the prevention and repair of gynatresia (vaginal blockage or stenosis), as well as urinary incontinence at the time of the primary operation (67). Approximately 10% of women were found to have gynatresia after the first repair. In another study, repair of the fistulas worsened gynatresia in 17 cases, in addition to twelve patients having dyspareunia (painful sexual intercourse) and three others with apareunia (inability to have sexual intercourse) (68). Similarly, a cross-sectional study to assess the health, social, and psychological problems encountered by women with treated and untreated fistulas was conducted in seven administrative regions of rural Ethiopia.

The in-depth interviews revealed that while treatment improved family and social life, some social and sexual problems remained (8). The most common physical complaint being that sexual intercourse was painful and could not be tolerated; with six saying they did not try to have sexual intercourse

after the operation because of fear of fistula recurrence in five, and because of incontinence in one. Of those who were not having intercourse following surgery, 80% were divorced, separated or widowed. Additionally, in a report which interviewed adolescent girls and women living with fistula and their family members, more than half of the 568 women seeking treatment at two national hospitals in Mali, from 2000 to 2002, were no longer sexually active (6). In Tanzania, 10-25% of the women who had remained married said that they did not have sexual relations with their husbands after their fistula (11).

Safe future delivery

As shown above, it is clear that successful reintegration for some means having more children. However, this act in itself may also hinder the process if there is a risk of recurrence of the fistula that may break her social connection again. This recurrence of another fistula is more likely to have a failed repair because of the law of diminishing returns (63).⁶³ This is not clear cut however, and it seems to depend on whether the pregnancy results in a live child or not. In a study in Zaria, pregnancy outcomes were followed for 82 women after the repair of their fistulas. All desired a pregnancy because of previously bad obstetric histories, which included an 87% stillbirth rate. In addition, 34 multiparous women also cited bad obstetric histories (e.g. prior stillbirths or infant deaths) as their reasons for trying for another pregnancy. After a repair to pregnancy interval, ranging from 10 – 25 months, 74 successful live births were achieved in the hospital as advised. The nine vaginal deliveries and 65 caesareans resulted in fistula recurrence in only two cases. One in a woman who had had three previous repairs and delivered by caesarean, the other, in a woman with two previous repairs who attempted a vaginal delivery at home because there were no nearby facilities (69). Both had live births and remained married. One woman had two pregnancies after her first stillbirth and subsequent fistula repair. The second resulted in a stillbirth vaginally and the second in a live birth but with fistula recurrence. Of the six women who had stillbirths, five were subsequently divorced as they had no other living children. The other remained married as she had a live birth from her first pregnancy.

Repaired reintegrated woman from FORWARD Nigeria with a live child.



At the Bahardir Fistula Centre in Ethiopia, when patients become pregnant again, they are encouraged to return to the hospital and wait for a caesarean section – currently thought of as the safest mode of delivery following fistula repair. The centre has had nearly 200 deliveries over the last few years and there have been no fistula recurrences. During the same time span, nearly 40 women have returned after trying to have their babies back in their villages. All the women lost their babies and all had a repeat fistula (70).

Some reintegration programmes like Dimol in Niger provide caesarean sections free of charge to all women who have undergone fistula repair to prevent the recurrence of fistula (10,71). Management differs in Nigeria however, with the mode of delivery tailored to the extent of the damage. In FORWARD, for instance, 25 out of its 145 residential clients up until 2007 had had successful vaginal deliveries with no fistula recurrence. Nineteen of these were women who had been to antenatal clinics but decided on home births with the assistance of traditional birth attendants (23).

Improved psychological health

Counselling is frequently cited as necessary for reintegration to occur because of the psychological trauma women experience as a result of losing their status and value in society, as well as the stigmatization which can cause many to isolate themselves out of shame (11,15). For instance, it has been shown that as many as 97% of women screen positive for depression and anxiety that could lead to other forms of mental health dysfunction (8–9,12-13,24,54,59). Some women even contemplate suicide (41,50,72,73) or express constant worry about their future, such as not being able to have more children, never being able to marry again, or never being repaired (11,14).

Studies however, show an improvement in mental health and social reintegration, almost entirely as a result of a successful operative repair—defined as anatomical closure without continuing urinary incontinence.

For instance, a prospective cohort series of 51 women with fistula, from the Barhirdar Hamlin Fistula Centre in northern Ethiopia, looked at the response to a mental health questionnaire both on admission and just after fistula repair (72). The women were screened using a shortened version of the General Health Questionnaire (GHQ-28) designed to detect anomalies in four areas, namely social dysfunction, somatic symptoms, anxiety/insomnia and depression. Before repair, 100% of women tested positive for potential psychiatric disorder (whereas 32% of controls tested positive). Two weeks after the repair, if the women were completely cured, only 29% tested positive: about the same as the control rate. This was in the absence of psychiatric or psychological support, and despite the mean time from the antecedent event to presentation of fistula being three years. However, if they were not cured (i.e. their operation failed or the fistula was closed but were still incontinent), then 100% still tested positive. The difference in prevalence of screen-positive women was statistically significant (chi-square test, $P=0.003$) as was the difference in median score (Mann–Whitney U test, $P < 0.05$). Similar results were found when women were followed up after six months. If women were still incontinent following their primary repair, they did worse in the questionnaire (54). And the last in a series of four thematic briefs developed from a study in Tanzania, which explored the changes in the lives of 61 women following fistula repair, reported that at least 50% of women highlighted the emotional impact of repair on their lives – feeling better about themselves after repair and referring to their return to health as “a miracle.”(11)

So for a good number of women, surgery may reverse psychological dysfunction and go a long way in bringing about a return to community and a normal lifestyle. However, counselling is still thought to be essential for women with fistula as it enables their medical and social evaluation to ensure their needs are met. Especially those needs that enable them to seamlessly return to their families and communities after repair.

Psychosocial counseling

“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.... After I was operated on, I was returned to the mental ward again. You realize, I am not dead, but I am not living.” (5)

In some women psychological dysfunction continues despite repair because their reintegration experiences may be impacted negatively, secondary to the degree of isolation and stigmatization experienced while living with fistula (29,31). This is in line with studies indicating that women who were repaired struggled with emotional distress such as losing their child during the pregnancy (55). Even a study which highlighted the improved quality of life and social reintegration after fistula closure found that one-third of the women manifested ongoing distress on follow-up (26).

In addition, it has been acknowledged that girls and women with fistula, whilst sharing a number of common experiences, differ in their varying need for family and social support, livelihood and income generation, and education and training. If the initial disruption experienced by the woman is high (e.g. she is divorced, is back living with her relatives, has no future child-bearing capacity, does not have a normal vagina for intercourse or is still leaking post-repair) she may need additional help (44).

To combat these, several reintegration programmes (23,41,71) offer counselling to aid women in defining their major problems. This is accomplished by exploring answers to questions, such as how long she has lived with the fistula, if her child survived or died, if she has other children, if she has a source of income, if she is married or has a supportive family, and if she is suffering from a psychiatric condition because of her fistula status. It can also help determine if learning a skill would transform her economically, and give her a skill appropriate for her individual preferences and socioeconomic conditions. Such individual counselling also helps ensure that, as highlighted in the IOFWG report, reintegration assistance is determined by what the woman wants for herself (43). So for example, counselling can help identify a woman who needs further intervention, either because they request it or because their status warrants it.

After surgery, counselling also helps assess her level of reintegration into her family and community, as well as help to identify women who require additional assistance. This counselling probes whether they have regained normality in their life at home, with questions related to social interaction, working ability, marital status, sexual intercourse, menstruation and subsequent pregnancies (29).

Health education

In several reintegration programmes (see Social Reintegration in Practice section), health education is given where women and their families are counselled about about hygiene and nutrition, how to take care of themselves during the postoperative period, how long to abstain from sexual activity after surgery, family planning, and the need for antenatal care in subsequent pregnancies. Women also learn about the medical nature and cause of their condition.

As such, counselling is considered important to a woman's ultimate reintegration as it ensures the dispelling of any myths and the minimization of behaviours such as inappropriate and delayed treatment which may make recurrence more likely (5). For instance, there have been reports of women

blaming their pre-existing vaginal stenosis on the surgeon and the fistula repair (41); a situation which is avoided by adequate counselling about the nature of the initial injury. And in several studies, a diverse range of perceptions and misconceptions on the origins of fistula were cited by women such as it being the result of evil spirits, a curse, or a sin such as promiscuity (6,8,13,59). And in others, most women with fistula and their families believed their condition was caused by factors related to the delivery process itself, such as the use of delivery instruments, people inserting their fingers into the vagina during labour (11,50) or the doctor accidentally piercing the bladder (14). In some cases, young first-time mothers have blamed their husbands for the problem and vowed never to marry and have children again (59).



Another questionnaire-based survey sought to determine the knowledge of women about causes of the fistula and their attitude toward measures that would prevent future occurrence (74). Of the 130 studied, 33 women did not identify prolonged obstructed labour as the cause, and either attributed their condition to God/destiny or to the operation that was done to relieve the obstruction. As a result, they would not want to have a hospital delivery in their subsequent pregnancies and (32%) would still not change from “risky obstetric behaviour”. From the focus group discussions held with the

maternity staff to ascertain the content and quality of existing counselling, it was confirmed that pre- and postoperative counselling was inadequate. The study concluded that mandatory provision of accurate and appropriate information, and education to all fistula women and their relatives or spouses, by trained counsellors, should be ensured. Such information and education should emphasize the etiology and management of obstetric fistula in order to prevent a recurrence.

Clinical counselling

Counselling is also seen as an essential adjunct to surgery as women may lack knowledge about their current condition, or information about maintaining their health after repair, especially for women with continuing incontinence (24,29,72). In one study, some women did not try to have sexual intercourse after the operation, because of fear of fistula recurrence (8). In another, several women, especially if they were childless, indicated that their biggest desire was to have children however, many were also worried if they could conceive or go through childbirth as the fistula might recur. There was also concern that their future husbands would not accept having only one or two children, as was prescribed by health personnel, as a means for women who had been repaired to protect their health.

A study conducted qualitative interviews with 15 women returning for follow-up after their fistula repairs and five accompanying family members in Eritrea. The study found that though many women stated improvements in their condition, many continued to have problems with incontinence and sexual health (75). It was also found that both new and returning patients lacked specific information about their condition, what to expect in terms of treatment and recovery, and how to care for

themselves. The findings pointed to a need for improved information, counselling, follow-up, and social services for women who develop obstetric fistulas. This is in line with other studies which showed that though treated women received pre-operative counselling and guidance on the recovery period, they were not able to obtain post-treatment counselling services after discharge (55). Even those successfully repaired noted that their bodies are “just not the same as before the fistula”. Many expressed fear of developing another fistula in future pregnancies. They also stated that they had specific questions about sexual function and fertility, and wanted to have access to a provider who could answer these and other questions they might have in the future. Many women also reported struggling with physical problems including pain when farming, with 76% indicating that they need further medical attention, mostly for abdominal and back pains.

It is also felt that counselling is important to ensure women are realistically informed of the extent of their condition, the likelihood of success of the operation, and of the steps that might be taken to help if the operation does not succeed (1). A study among 15 Eritrean women living with fistula found that providers gave only very limited information about their condition and upcoming surgery, as well as what symptoms they would experience during recovery (75). There have been reports of women blaming their pre-existing vaginal stenosis on the surgeon and the fistula repair (41); a situation which is avoided by adequate counselling about the nature of the initial injury.



In addition, studies show that women with continuing incontinence following unsuccessful repairs continue to have high levels of mental dysfunction and should therefore be offered a great deal of psychological support (72). These “incurable” women need specialized counselling to help them overcome the trauma, and help them make informed decisions on the best way forward. Urinary diversion may be offered but may not be what the woman wants or may not be feasible in her social or cultural context. She may prefer leaking rather than diversion. There are also reports of providers who are reluctant

to disclose the prognosis to incurable women, perhaps because of stripping away any hope from the woman. The result may be that the woman stays at or around the health care facility, for many years, in the hope and belief that one day she will be cured (41). It is felt that individual counselling can help such women establish what would be the best way they can support themselves and get a new life.

Peer support and family counselling

Peer support is seen as a great mental counselling tool as women have often become “victims of social and cultural ostracism.” As a result, they withdraw themselves from their communities out of shame and humiliation and learn the role of being different (14,15,50). This can be compounded where institutions with their constraints of traditional (expert/patient) relationships offer a culture of “illness” and disability as opposed to the intended culture of health and ability (76).

Some dedicated reintegration programmes give women the capacity to connect with other women with similar experiences in a relationship of support and self-help (29,71). This then becomes a natural re-introduction towards their re-entry to their communities. Women start to understand their problems within a safe social context, and from vantage points of personal worth and social power rather than pathologizing themselves (76). The common cry– when fistula women meet others like themselves in an atmosphere of support and learning– being that they now know they are not alone. As such, the residential centres of FORWARD and Delta Survie (see Social Reintegration in Practice) provide a place where women can live, eat, cook and talk with others. Women stay at the centre before and after undergoing surgery and mingle with whom they can identify and bond with to aid their recovery.

It has also been found helpful in reintegration programmes to include husbands, families and community members in the counselling sessions. This helps to demystify the condition, with explanations and knowledge that the woman is now healed. In addition, it helps to ensure understanding of the need for postoperative advice, such as the need to abstain from sexual intercourse following surgery and the need for obstetric care in subsequent deliveries (29,41,71).

Family Counselling –
Fistula Foundation,
Nigeria.
(Courtesy Musa Isa)



Women in FORWARD
Nigeria, cohort 2010.
(Courtesy Gloria Esegbona)



Peer support in FORWARD
Nigeria – storytelling and
singing.
(Courtesy Rahmat Mohammed)



Counselling curriculum

Lack of high quality and appropriate forms of these types of counselling were noted when Engender Health EngenderHealth (EH) conducted needs assessments on fistula services in twelve developing countries. The results indicated that the staff repeatedly ask for technical assistance on how to counsel fistula clients (77). In some cases, they practiced counselling as the situation demanded, but felt unsure of the most important messages. In other cases, they had a sense that they should be doing some kind of counselling, but did not know where to begin.

In response to such expressed need, EH developed the first formal fistula counselling curriculum. The curriculum was tailored to the specific comprehensive counselling and information needs of women living with fistula, focusing on their pre- and postoperative needs, and addressing techniques to help women avoid future pregnancy complications. To ensure an evidence-based content of the curriculum, EH conducted an extensive literature review, and convened a meeting of fistula counselling experts in Kampala, Uganda in March 2005 (78). The goal of this meeting was for counsellors, health educators, social workers, doctors and nurses, to share best practices and identify key components of the curriculum, and to learn about critical issues for counselling fistula clients. The topics included how to identify the similarities and differences between the needs of fistula patients compared to other patients, to discuss at what point in the spectrum of care it is most appropriate to counsel fistula patients on key issues, and to identify barriers to counselling (10). After the meeting, EH also held focus group discussions (FGDs) with 29 women with fistula at Kitovu Mission Hospital in Uganda to collect information on their needs and concerns. Participants included women varying in age from 18 to approximately 50, so that the curriculum could be adapted to the individual needs of fistula patients in various settings. These included women who were waiting to receive treatment, those who had undergone several unsuccessful repairs, and those who had experienced successful repair.

As a result, the curriculum, as it currently stands, is organized along the broad categories of:

- Information/education needs, including how the woman sustained her fistula, her understanding about her condition, information on what fistula is, future risk factors and how to prevent fistula from occurring again.
- Education and counselling on the use of family planning as well as good obstetric care, what the course of her treatment will be, referral for, as well as emotional support from providers.

TABLE 3 Tips to Improve Fistula Counselling Services (adapted from EnGender Health Counselling Curriculum)

1. Understand the patient's reality (e.g. illiteracy).
2. Drawing a diagram or using analogies to help explain how the fistula was caused and dispel misconceptions.
3. Work with former fistula patients as translators or counselors to overcome language and other barriers.
4. Counsel patient at all stages to prepare them for treatment and reintegration.
5. Initial counselling must often include key messages of acceptance of the woman.
6. Training should address providers' own potential biases and misconceptions about obstetric fistula.
7. Sharing "success stories" can be an important pre-op counselling strategy.
8. Involving a patient's family members and/or partner in counselling is key to a patient's overall success.
9. Support groups can be important to ease the process of re-entering society.
10. Patient's role in her own recovery process can serve as a key source of empowerment.
11. Repaired patient should leave with card including surgeon's notes.

The curriculum is designed to prepare providers to meet the information and counselling needs of obstetric fistula patients before, during, and following treatment, including referral for services and issues which may be outside the scope of the provider's responsibilities. Tips to improve the counselling service were highlighted (**Table 3**). The type of individual who gives the counselling was found to vary depending on the site's staffing pattern. But at a minimum, it was felt all facility staff should be sensitized to the counselling needs of fistula patients. The curriculum is currently being field tested in Bangladesh, Nigeria, Rwanda and Uganda.

One study evaluated the instant impact of the counselling curriculum developed by EH. Women were interviewed both before pre-operative counselling and again after postoperative counselling to assess their knowledge about fistula, self-esteem, and their behavioural intentions for health maintenance and social reintegration following surgical repair (79). In addition, two focus groups were conducted with a total of 19 patients assessing their experiences with the surgical care and counselling. Data from the questionnaires revealed significant improvements in women's knowledge about the causes of fistula, fistula prevention, self-esteem, and behavioral intentions following counselling. Focus group data also suggested increased knowledge and self-esteem as a result of counselling.

More socioeconomic support

The preceding discussion seems to suggest that most women reintegrate without any form of support if their fistulas are repaired successfully. However, it has been acknowledged that the degree of stigmatization and isolation inversely correlates with factors such as the socioeconomic situation of the woman and her family members, the length of time she has had the fistula, and her marital status – all determining factors in the possibility of post-treatment reintegration and “the sustained success of repairs” (10,13,49).

Complicating matters is also the fact that women differ within and between countries in their socio-economic status and thus, their need for support. A large series of East African women with fistula that looked at socio-demographic characteristics found that some of their results differed from those reported in other large studies (57). The results showed that 58% of the women had received some form of education: 30% completing primary school, and some having been to secondary school. A high percentage of the woman’s partners also received primary education. Similarly, spurious socio-demographic data was noted in a study of 239 fistula women in Zambia (80). One finding was that the age at marriage and at first pregnancy (median 22 years) was generally older than in previous studies (20,21). In addition, only a small number were divorced compared to previous literature, although this might be explained by the generational awareness alluded to earlier.

Other studies confirm the fact that it not always the case that women are abandoned by their husbands, cut off from family, and live a life of isolation and destitution. For instance, one study in Tanzania exploring social vulnerability to fistula showed that more than 50% of the 61 women with fistula who were interviewed were married before they sustained their fistula and stayed married after developing the problem, despite the fact that the majority of women had lived with fistula for two years or more at the time of the interview (11).

This contravenes many widely held assumptions about the impact of fistula on women’s marital status. In the same study, all of the women mentioned were supported by at least one person: if not a member of their family (e.g., parents or siblings), then a person or group in the community or an employer. None of the women were totally isolated and unsupported. Of the married women who stayed married after their fistula (n=30), the majority received support from their spouse or husband. Support was in the form of assistance in seeking treatment, financial support, emotional support and encouragement, and help with chores or with work. A study in Uganda, albeit with smaller numbers, showed similar support structures reflecting women’s positive relationship with her family (14).

As such, the need to base any socio-economic support based on the needs of individual women is crucial, and the in-depth counselling described in the preceding section can help to delineate these needs. Whilst there is not much by the way of research evidence of how to address the individual social challenges posed by having fistula (31), personal communication with reintegration programmes and a review of operational reports suggest that several main areas constitute this social support.

A space to stay

Rehabilitation and reintegration is not seen as a specific place or facility and there is recognition that a rehabilitation training centre and its techniques may or may not lead to rehabilitation outcomes (40). However, given the importance of the repair itself to ultimate reintegration, dedicated fistula repair centres aid women's reintegration for several reasons. These reasons include: providing a place for repair, a dedicated space for the women to recuperate and the time to introduce her to desired reintegration services.

For instance, the Babbar Ruga Fistula Hospital in Northern Nigeria (81); though its specific remit is not reintegration, the set-up is such that the hospital enables women to stay, if necessary, with extended members of their family, while awaiting repair, and for the weeks and sometimes months it takes to recuperate afterwards. There is a lot of open space and women literally set up camp in the communal grounds and buildings, cooking and bathing as they would at home, often with relatives visiting and staying as often as they are able to. Women and their relatives then see and feel that something is being done for them and ostracism is kept to a minimum. As such, the woman is never seen as separate from her family and usually seamlessly reintegrates back into her normal community once repaired.

Similarly, the residential rehabilitation centres of FORWARD, Dimol and Delta Survie (see *Social Reintegration in Practice*) provides a place where women can live, eat, cook and talk with others. Women stay before and for months after undergoing surgery. They are welcomed into a non-judgmental community of women with whom they can identify and bond with to aid their recovery. This then affords the much needed peer support discussed in the previous section as women help each other recover.

Fistula repair centres set up like Babbar Ruga are also beneficial for social reintegration for other reasons. Firstly, as many of the obstetric fistula women come from remote villages, they may be unable to financially go home and then return for their postoperative check-up. Designated centres can help circumvent a geographic accessibility problem and indeed some rehabilitation centres, such as the government run centres in Nigeria, are used more as a hostel than as a centre to receive rehabilitation support (37). In Ethiopia, the reintegration and treatment centres are in rural areas much closer to where the people live so that family support and subsequent postoperative follow-up is more likely to be achieved (82).

Studies and communication also suggest that having a place to recuperate for free, during and after treatment, also removes a huge barrier for women as the three- to six-month recovery requires that women rest, and refrain from sexual relations, both of which can be difficult to avoid if she has to return to her home environment (50). In one study for instance, of the 141 women attending for follow-up, six women originally discharged with a closed fistula and continent, came back with a recurrence or "late breakdown" of the fistula. Five of these six women reported an exacerbating physical event for the recurrence of their incontinence, such as straining, sexual intercourse, heavy work or being on a very bumpy road in a bus (54).

This has also been observed in Uganda (83) where out of a consecutive series of 756 women said to have been discharged home dry after fistula repair from three hospitals in Uganda, 16 (2%) were identified as having become wet soon after. This happened either on the way home or within one or two weeks, despite all having repairs for relatively simple fistulas. Possible causes cited included over-distension of the bladder due to the long and arduous journeys home many women face. One woman stated that she had a very full bladder but was too shy to ask the taxi driver to stop to empty her bladder and soon after became wet. Or that, as admitted by others, that there was early resumption of sexual activity or strenuous physical activity like farming in spite of contrary instruction. All women subsequently had a second repair with 14 out of 16 recorded as going home dry. This implies that their fistulas were small and leakage either avoidable or curable with catheter drainage if they had returned immediately as soon as they noticed they were leaking. Since becoming aware of the problem of postoperative leakage, the authors instructed women to wait for a week before setting off home and to return as soon as leaking occurs. However they also stated that none complied probably due to a travelling and financial issue.

In another study, although women were usually allowed two to three weeks to heal in the hospital post-repair, most felt they needed more time to recover (72). Women living far from the hospital opted to stay with relatives living close to the hospital until they felt ready to make the long journey home. In addition, those going home immediately after surgery lived with parents, and nearly all reported needing someone to help them at home while they recovered (typically a sister or mother) as they experienced difficulties resuming their expected social roles after treatment. They also mentioned that they were afraid they would develop another fistula from physical exertion or sexual activity, and/or experienced a lot of pain and weakness while working. Forty-eight percent of treated women reported persisting physical problems. The authors of the study felt that if women cannot be operated on immediately, rather than being sent away, it is appropriate to provide a waiting area close to the fistula unit where they can stay until they have surgery (72).

Women recuperating in the extensive grounds of Babbar Ruga Fistula Hospital, Nigeria.



Improved economic activities

Resuming work is perceived by many women as critical to re-establishing their place in society. As women are reported to struggle with economic difficulties, made worse by the fact that they may have never worked due to gender inequity or are unable to work because of their condition (2,55). Some women save money for years, for medical and transport expenses, and the delay increases the likelihood of medical and psychosocial complications. They may have sold all they have so they can travel to seek help. And once getting that help they may have to stay to recuperate – a burden if they have no money and are far from home.

Sambusa Making.
(Courtesy Becky Kiser, Trampled
Rose, Ethiopia)



Numerous studies state therefore, that for most women recovering from an obstetric fistula, work is the most important factor to help them feel “normal” again. Especially as most women were working to support themselves and their families before developing fistula (14,50,59). However, their condition affected their ability to work as they used to before, or limited their sources of income. Reasons cited included being in pain, concern about wetting themselves in front of others, or offending others with their smell. In addition, some were unable to work as hard because of feeling too weak, or tiring easily. This meant they could no longer provide for themselves and/or their families and forced greater dependence on husbands and family members both financially and with day-to-day tasks. This is an issue in itself as most may be living below the poverty line already (6,59).

In addition, there are reports that some women have had to resort to commercial sex work once they are repaired, as a way to seek an immediate income to survive, particularly those that have lived with fistula for many years (41).

For these reasons, training in income-generating activities (IGAs) is an integral part of the reintegration process for programmes. The aim of learning an activity – to give them a skill that they can use when they return home in order to improve their economic and social positions and give them a sense of autonomy and self-worth (23,29). In Liberia for instance, fistula survivors learn how to make and sell soap, flowers, baked goods, dresses and fabric. They can also become beauticians or learn baking techniques. More than 50 women have so far graduated from the social rehabilitation and reintegration programme. Already one result is that about half of the graduates from the programme are reunited with their husbands, whereas in the past, the figure was closer to 25% (86).

Learning Embroidery. Kwalli Rehabilitation Centre, Kano, Nigeria.
(Courtesy Musa Isa)



Others have started microcredit programmes where funds are given to women for income-generating activities, such as selling food or to purchase sheep or goats. These programmes include the community-based NGOs, Dimol and Solidarite, in Niger which also work to reintegrate women living with fistula by holding meetings with local authorities, the community and the patients' husbands and families to explain the causes and consequences of fistula (1,87).

Soap Making. Trampled Rose, Ethiopia.
(Courtesy Becky Kiser)



Teaching IGAs is also said to help in another way as findings do suggest that women may need to engage in less strenuous work for at least one year after surgery to allow them to fully recover. Some studies do report that the majority of women recover, with the ability to support themselves and their families financially after repair. Almost all are able to perform domestic chores, such as fetching wood and water, farming and cooking (11). Others report physical strain as a barrier to complete

recovery after fistula repair especially if they are from rural areas and it is back-breaking work like farming (49,54). These findings suggest the need for alternative non-labour intensive ways to generate income for at least the first year post-surgery, such as bead- and cap-making, which are light skills (60).

Lastly, the long postoperative period that women usually have to undertake is also thought of as providing an opportunity to improve women's socio-economic status through skills training programs before they return to their communities. Women usually require at least two weeks of in-hospital care, combined with several weeks of pre-and postoperative support to ensure adequate healing (88).

Knitting skills training in the Kwalli Rehabilitation Centre, Kano, Nigeria.
(Courtesy Musa Isa)



However, learning a skill as an approach cannot be a “one-size fits-all” approach as mentioned by many programmes. For instance, in the Delta Survie reintegration shelter, the skills the women learn in craft- and jewelry-making to sell to the tourist market has been noted not to always translate in real life (60). Women who leave the centre rarely continue to make jewelry. When asked, most women said that they lacked the means to start a business, and even if they had, that the products wouldn't sell as many women come from remote villages where the tourist trade is barely, if at all, existent. Even women who come from larger cities know that the market is already flooded with artisan products and that competition would be hard, especially once removed from the resources offered by the shelter.

An evaluation of rehabilitation centres in Northern Nigeria concluded that the “facilities may not equip the women with skills that are useful for economic activities in their own environment and that innovative, needs-specific methods should be adopted for future interventions in accordance with the economic realities of the communities and market availability” (89). In Niger, Réseau Pour l'Élimination de la Fistule Obstétricale (REF) organized an evaluation of social and economic reintegration activities in the country. Their evaluations showed that though the bulk of financial support provided to women post-treatment was for training in small business ventures (e.g., animal husbandry), there was a mismatch between the training received by the women and the activities they actually lead, once back in their communities. The majority of women returned home to resume traditional family roles (43,90).

There is also the issue of whether those entering the programme actually require the services. For instance, in Kinshasa, Bas Congo and Equateur in DR Congo, it seems that the main criterion for entering into a post-surgery income-generation programme is not the woman's needs, but rather her proximity to the NGO training site (43). This is because local NGOs receive lists of women who have undergone surgery containing very limited information and then contact the woman to determine if and what type of support she requires.

It is recognized in other social reintegration fields that if the skills are not based on an analysis of what a person specifically needs, it will not lead to recovery or reintegration (40). As such, this problem of inappropriate training may be overcome by the individualized approach in place in some programmes. For instance, social support is implemented differently in Kindu, another region of DR Congo, where the community volunteers providing social support are closely associated with the medical services at the Maternité Sans Risque hospital. They are able to take individual needs into consideration, because the community volunteers are in a good position to assess the needs for reintegration when the woman who has been repaired leaves medical treatment (43). Women are then supported with grants and equipment in tandem with their economic backgrounds or existing skills. Patients sign an agreement to work with a tutor who can help them build a business based on their existing or desired skills. The signed agreement entitles them to a bank account and training in business and financial literacy, so they know how to keep their books. Start-up kits then provide them with the essentials to begin a business of their choosing. For example, a seamstress might be given a sewing machine and fabric.

It is said that more than 350 fistula survivors have benefited from such social reintegration programmes and have been able to improve their living conditions with the training received. Similarly, FORWARD offers a number of skills which women can choose from based on their interests, and the context into which she will return to (23,29). In addition, small business management principles are taught to help patients develop the skills necessary to manage their own businesses when they return to their villages.

It seems it doesn't matter what is offered, as long as it is a skill which is commercially viable within their normal context, and what the woman wants and needs. It cannot harm women to learn a skill, or be educated, as long as this does not unduly keep them away from their communities. It has been reported that some women want to get back home as soon as possible after repair, to prevent divorce, or her husband taking another wife, but are kept away from their matrimonial home in a bid to teach her a skill, she may not use, or may not even be appropriate (41).

It is not practical to think that all treatment centres can feasibly offer IGA services as it is time-consuming and has a cost implication which may divert resources from the quality of fistula repair and other treatment services. A lack of resources and materials will mean that the variety of skills and competencies provided may not be the most appropriate for the individual preferences and socio-economic situation of the fistula patients. However, it has been suggested that repair centres could follow the model of the Somine Dolo Hospital in the Delta Survie partnership, by finding local groups with whom to work (43). Another is the model, FORWARD Nigeria, who has worked in

close collaboration with other organizations, especially government programmes geared towards the empowerment of women, such as microcredit and poverty alleviation, not just because of the skills training often included but the economic value added (23,29).

Family support

In a study where the post-treatment psychosocial and economic situations of six women with fistula were analyzed to find out how women with fistula respond to rehabilitation and reintegration services, it was surmised that “family is the core social institute that critically intersects with the possibility of success following postoperative reintegration therapy.” The peak of stigma and social discrimination occurs when patients are alienated by close family members, such as parents and siblings, to whom they are primarily dependent for economic and psychological support (49). This is more likely to happen when their condition is seen as being chronic rather than an acute affair which can be coped with.

Many reports describe how fistula places a heavy social emotional and financial burden on survivors and their families. For instance, in the form of incurring substantial costs in seeking funds for treatment, buying resources (soap, water, etc.) to manage her condition, transportation, and for food and upkeep while in the hospital. Money often raised by selling assets such as land and livestock, drive families, usually on low incomes, further into poverty.

Husband and children waiting for a woman with fistula undergoing repair in the grounds of Babbar Ruga Fistula Hospital.

(Courtesy Gloria Esegbona)



In addition, families often have to forgo the loss of the woman’s contribution to work at home, on the farm, or in income-generating activities, as well as the income of the family members who had to forgo work and income to accompany the women for treatment (11,14,50,59). Additionally, women with fistula also indicate that family members suffered from stress and worry about their having fistula or faced ridicule in the community. Despite this increasing depth of poverty, reports are mainly of support (11,14,51) and families on the whole manage until women are given no hope for a cure because of true inoperability, misdiagnosis, inexperience and inappropriate care, or sent away for a three-month period to heal before surgery. Research suggests that it is then women are “gradually” (58) ostracized because the fistula becomes an unmanageable “chronic condition beyond the family’s understanding and capabilities to care for the woman” (51).

As such, in some reintegration programmes, early repair within three months is emphasized, and counselling and support is also provided for the women's family members who are tracked down and invited to visit and support her during her rehabilitation. This is an important part of counselling the family, directly and indirectly, by letting them see their relative as still part of the family, that she can be helped, and educating them on the nature of her woman's condition and what is required for full recovery. It also helps determine what socio-economic needs the woman may have (14,23,29). This also serves as an opportunity to ensure that family members who often play the most critical role in determining access to essential obstetric care (5,6,14) are aware of the importance of seeking adequate help in the next pregnancy and birth to reduce the chances of fistula recurrence.

Community support

“Social reintegration is about preventing the fistula occurrence/recurrence cycle”(91)

A few fistula reintegration centres offer institutional pre- and postoperative support, including the skills training and income-generating activities discussed previously. The majority, however, are a mix of centre-based and community reintegration approaches that, as well as offering such skills training, also involves linking with communities to discuss the return of the women who have been operated on. As in many communities, especially in rural areas, very little is known or understood about the risk factors and causes associated with fistula development. It may be seen as a curse or the fault of the woman and she may not be accepted back even if repaired. Even if she is accepted, there is great risk that she will return with another fistula if there is lack of understanding that she needs to seek appropriate health advice in her next pregnancy. Thus, changing social and cultural attitudes in the community are central to helping reintegration and also preventing what has been termed the “fistula occurrence/recurrence cycle” in subsequent pregnancies; either for the woman herself or women within her community (91).

Repaired reintegrated girl from FORWARD Nigeria who died in her second pregnancy because of lack of access to hospital care.

(Courtesy Rahmat Mohammad)



There are a multitude of different community approaches being piloted across a number of countries (1,37) that are best understood by looking at the specific programmes detailed in the Social Reintegration in Practice section. However, there are a number of common features worthy of analysis, such as community outreach – where reintegration activities extend to community mobilization and Information, Education and Communication (IEC) and Behaviour Change Communication

(BCC) activities to address the social marginalization that separates women from their families and communities. As it is believed that the exclusion and stigmatization by society worsen the psychosocial and economic challenges of reintegration for women (41,49,84,87).

Fistula Foundation Nigeria project meeting with Emir of Kano to explain its fistula sensitization campaign.
(Courtesy Musa Isa)



The outreach visit is essentially a sensitization campaign which encourages the participation of men, gatekeepers of the community such as religious leaders and traditional rulers, in order to change their attitudes towards women living with fistula. The aim is to reduce the stigma surrounding the condition, and champion the demystification of traditional norms and practices pertaining to women and childbirth, thereby creating an atmosphere conducive to their return to their communities of origin. The IEC/BCC activity is also used to detect and refer women with fistula to repair services as soon as possible, to reduce the level and duration of stigma they are exposed to and facilitate a seamless reintegration back into the community (41,85). Community outreach also helps to support and guide women, to prevent recurrence of their fistula and improve future pregnancy outcomes. The outreach also advice women on how to enter into a dialogue with family members and the community about what they have experienced and how a successful fistula repair enables them to return to a full family and community life (44). Sensitization is conducted through a variety of mediums including music, radio broadcasts, public announcements, speeches, posters, leaflets, and workshops. The result is a symbiotic model of psychotherapeutic interventions that embraces the local knowledge and culture and helps in preventing fistula (41).

Community advocacy in Bangladesh.
(Courtesy Roushon Ara Begum, UNFPA)



It has been said that prevention programs, like community awareness campaigns, are unlikely to truly succeed if not done in partnership with the women themselves. As by virtue of having lived with fistula, they are in essence more knowledgeable than any number of “experts” combined and have more to gain by having fistula eradicated (51). In addition, having the main stakeholders (women with fistula) perform the IEC/BCC activities in their local communities creates a quicker, more sustained change in “people’s actions and attitudes towards the causes of ill health and is key to achieving the goal of good health for all” (92). Especially as they can help circumvent the logistical difficulties of travel and communication, particularly in rural areas.

For a number of programmes the involvement of women in IEC/BCC has taken the form of training former fistula patients to become community and peer educators, ambassadors, and motivational mobilisers. These community fistula advocates (CFAs) have been taught communication techniques such as public speaking and interpersonal communication.

Community Fistula Advocate from FORWARD Nigeria counselling a new cohort of women with fistula.
(Courtesy Rahmat Mohammed)



This is because it is felt that advocacy by CFA encourages communities to take ownership of the fistula issue, and that they can better facilitate the understanding of the linkages between fistula and improved maternal health (93). The goal is that after returning to their communities, the CFAs can become empowered agents of change using social events to raise community awareness about the causes of fistula, how to prevent it and the availability of treatment. This helps to reduce stigmatization and isolation from family and the community, and mobilize acceptance in the community, especially in men and community leaders. They are also encouraged to create a network of fistula advocates within the community, and some programmes like Bangladesh are thinking about helping them become the community-based trainers of newly repaired women.

Several countries are now working with CFAs, each of whom is working in her own way to sensitize communities, providing peer support to women living with fistula, and advocating for improved maternal health. In Côte d’Ivoire, 20 fistula survivors received training in educational communication techniques and now speak at community gatherings to encourage behaviour change. They also work with the media and discuss fistula prevention and treatment on radio and television programmes. A pilot effort in Eritrea provided training to 21 fistula survivors to work as maternal health volunteers — focusing in particular on counselling, safe motherhood, and the prevention and

treatment of obstetric fistula. Trainees are now conducting community mobilization and educational sessions with pregnant women to educate them regarding the importance of antenatal care and giving birth in hospitals (43).

Lastly there are programmes such as Fistula Foundation Nigeria who escort fistula survivors back to their communities and believe that there needs to be preparation of: (i) the woman by the social workers or other related professionals to return home, and (ii) the members of local communities to receive her to ensure women are able to return to their communities successfully. Such family reintegration requires social workers to be trained to adequately help explain to the family and community the causes of fistula (41).

Training repaired fistula women as community fistula advocates.
(Courtesy Roushon Ara Begum, UNFPA.)



6.4 Social Reintegration in Practice

“The battle against fistula is a just cause. Reintegration is the poor relation of this war, this component must receive very special attention. Innovative and promising strategies can help make a difference.” (94)

A report in 2003 by EH, when it partnered with the UNFPA to conduct a needs assessment in nine African countries and personal correspondence with several reintegration programmes, has found that there are not many reintegration models specifically for women affected by fistula with published results (77). In addition, there were few active programmes (facilitating education and vocational training opportunities, which are followed up and led to an independent social reintegration) compared to passive programmes (where women are given training but are not followed up to ensure enhanced social functioning) (**Table 4**) with interventions for social reintegration. Example of social reintegrations include family reunification (or finding alternative care if reunification is impossible), providing education and training, devising appropriate strategies for economic and livelihood support, and providing psycho-social support.

Similar findings were found some years later in 2009 when a midterm thematic evaluation was done of UNFPA national fistula programmes. They conducted field missions to Bangladesh, Nigeria, the Democratic Republic of the Congo and Niger; and performed desk reviews of national fistula programmes in Kenya, Pakistan, Sudan and Tanzania, as well as sent questionnaires to 40 UNFPA country offices (CO) receiving 24 replies with a response rate of 60% (37,43). The consortium found provision of reintegration services to be a weak link in the fistula management process with few formal initiatives by the government or other service providers. Many questions were raised about the effectiveness of social services for support and reintegration of women following fistula surgery. Apart from individual accounts of major successes, there was no systematic record or evaluation that would allow any statements about the overall effectiveness of the programme. The findings in 35 facilities from nine African countries ranged from no support and no data on reintegration (most facilities and countries), to covering for cost of food and clothes only (UNFPA and EH). The few NGOs that had reintegration as their specific remit offered different and often poor levels of pre- and post-operation support, including health education, training in life skills and competencies for smooth reintegration in their communities and for income-generating purposes. Overall the availability and accessibility of rehabilitation services was found to be insufficient compared to the number of women who had had surgery. For example, Cote d’Ivoire reported that only 27 of 119 women who received treatment in 2009 were fully reintegrated into their communities.

The experiences in some countries described below have been chosen for their innovative approaches to address social reintegration. However, most have not yet been rigorously evaluated and many in fact are only in pilot stages. This section is designed not to present programme models for replication, but to highlight emerging ideas and practices that may become proven, sustainable strategies in the years to come, and help to inspire innovative solutions.

TABLE 4 Social Reintegration Centres

| Country | Centre (s) | Type of Programme ¹ | Overview | No of Women Benefited | Strengths | Challenges |
|-------------------------------------|--|--------------------------------|--|---|---|--|
| BANGLADESH | Fistula Training and Rehabilitation Centre, Dhaka funded by UNFPA | Active | See main text | 235 | Potential to use CFA to extend into community | How to make an effective but costly model replicable for others to follow, both in a facility-based and in a community-based context. |
| DEMOCRATIC REPUBLIC OF CONGO | UNFPA partnerships with local NGOs in Kindu, Kinshasha, Bas Congo and Equateur | Passive | Two variations: 1) through community volunteers (before, during, after surgery), or 2) through NGO staff | 10-15% of women access post-surgery social support Total: 127/9392 | In Kindu, volunteers are in a good position to assess the needs for social reintegration support. | The proportion of women who access these services remains small (as compared to the number of women who had a surgery). It is not clear whether those not benefiting from the programme did not require the services or whether they could not access them for a variety of reasons. |
| KENYA | NGO Sentinelles | Passive | Established partnerships with West Pokot hospital in order to provide some social support. | N/A | Potential to build on Ambassadors of Hope (i.e. group of former fistula patients). | Poor follow-up Only able to reach out to a limited number of communities. |

continued on page 215

TABLE 4 Social Reintegration Centres, *Cont'd*

| Country | Centre (s) | Type of Programme ¹ | Overview | No of Women Benefited | Strengths | Challenges |
|---------|--|--------------------------------|---|--|--|---|
| NIGER | The focal point for the organization of social reintegration is the Ministry of Promotion of the Woman (Ministère de la Promotion de la Femme), which it delegates to the NGOs DIMOL and Solidarité. | | Three main components of the social reintegration programme are: 1) information on reproductive health (need for ANC, prophylactic caesarean section); 2) training in income generation activities (IGA) and 3) provision of around 50,000 FCFA (\$110) to start the IGA. | 567 women benefited from the programme 2005-2008 | | The effectiveness of the current income-generating activities for fistula survivors is not clear. |
| | Solidarité, Zinder | Passive | Founded by Dr Lucien Djangnikpo, a fistula surgeon who found that women, particularly those who have had fistula for 10 to 15 years, were likely to experience extreme stigmatization and resort to commercial sex work once repaired, as a way to survive. Now women are given a \$125 microcredit loan to start a business. Provides a holistic approach to obstetric fistula | Up until 2007, Solidarité has contributed to the treatment of 745 women in the Zinder region, 327 of whom have been fully reintegrated | Work to reintegrate women living with fistula, by liaising with the community. | |

continued on page 216

TABLE 4 Social Reintegration Centres, *Cont'd*

| Country | Centre (s) | Type of Programme ¹ | Overview | No of Women Benefited | Strengths | Challenges |
|----------------|---|--------------------------------|--|-----------------------|-----------|--|
| NIGER | Dimol | Active | See text | | | |
| | FORWARD Nigeria residential and community project | Active | See text | | | |
| NIGERIA | The State Ministries of Women Affairs and Social Development (SMoWASD) rehabilitation and reintegration centres: Kwalli Rehabilaitaion centre, Kano Babbar Ruga Rehabilitation centre, Katsina. | Passive | Receive women in their postoperative period Training related to functional literacy and numeracy, knitting and sewing or income generation activities, and sometimes women can receive grants. | Unavailable | | Because of lack of resources and materials, the variety of skills and competencies provided is usually limited and not the most appropriate for the individual preferences and socio-economic situation of the fistula patients. Sometimes the centres are used more as a hostel than as a centre to receive rehabilitation support. |
| | Kaduna State Rehabilitation Centre | Passive | A new centre for repaired women built in cooperation with Rotary International and FCEIS (Family Care Eduvission International Services) and sponsored by the Japanese Embassy. All women are rehabilitated medically and many of them receive vocational training in different skills like sewing, knitting, and spaghetti-making. Some of the patients are given a microcredit to enable them to start businesses. | | | |
| | Fistula Foundation Nigeria | Active | See text | | | |
| | Koochi Goth Women Hospital Rehabilitation Centre | Passive | Established reintegration services through the regional fistula centre. Supported technically and financially by UNFPA. | | | |

continued on **page 217**

TABLE 4 Social Reintegration Centres, *Cont'd*

| Country | Centre (s) | Type of Programme ¹ | Overview | No of Women Benefited | Strengths | Challenges |
|-------------------|---|--------------------------------|---|-----------------------|-----------|------------|
| SUDAN | The National Centre for Rehabilitation and Social Integration of Fistula Patients | Passive | <p>Opened in 2009, with a capacity of 40 beds. It aims to complement the work of the existing Abbo Fistula Treatment Centre in Khartoum.</p> <p>The centre provides psychological rehabilitation services.</p> <p>During fistula treatment campaigns/camps, it works with NGOs with support from UNFPA, to offer women the opportunity to gain income-generation skills like soap and macaroni-making, sewing, knitting etc. In addition she is given advice on family planning as requested.</p> <p>Similar centres are to be established in the Darfur States.</p> | | | |
| TANZANIA | The Mabinti rehabilitation Centre in Dar es Salaam | Passive | <p>Set up in 2007 by the Comprehensive Community Based Rehabilitation Hospitals fistula ward (CCBRT) from where it receives patients. During an 18-month period, 18 women acquire skills in order to gain socio-economic security and empowerment such as sewing, screen-printing and business management. They also learn life skills such as hygiene, family planning and HIV prevention. Women also learn how to use recycled materials in innovative ways. For example, area businesses hire the centre to produce fashion-related items that are made from discarded billboards. After finishing the course, each woman is supplied with a starter kit containing a sewing machine, patterns, scissors, beading utensils and a supply of fabric and beads.</p> | | | |
| THE GAMBIA | Shelter Gambia in Bakoteh | Passive | <p>Established in June 2009, to empower women after having surgery.</p> <p>A facility has been donated by the government in which women stay for about two months (with their children) after being discharged from hospital, if necessary, during which time they receive health education. The cooperation with a centre nearby, also enables women to learn skills like sewing, soap-making, tie and dye, etc. When the women go home they are given a sewing machine.</p> | | | |
| LIBERIA | Fistula Rehabilitation and Reintegration Centre (FRRRC) in Jacob Town, Paynesville. | Passive | <p>Launched in 2007 by the Government of Liberia, with funding from UNFPA.</p> <p>In a four- to six-month programme, a proportion of women who have undergone successful surgery are trained in tie and dye cloth-making, tailoring, pastry making and cosmetology. As part of this training process, women are provided lodging, literacy, vocational skills and health education.</p> <p>Women receive post-training starter kits, to facilitate their engagement in income-generating activities and their reentry into their communities. A subset of these women is trained as community and national maternal health advocates.</p> | | | |
| GUINEA | The Urban Development Commune (UDC) | Passive | See text | | | |

continued on **page 218**

TABLE 4 Social Reintegration Centres, *Cont'd*

| Country | Centre (s) | Type of Programme ¹ | Overview | No of Women Benefited | Strengths | Challenges |
|----------|---|--------------------------------|--|-----------------------|-----------|------------|
| MALI | Delta Centre de survie pour femmes avec fistules | Passive | See text | | | |
| | Trampled Rose | Passive | See text | | | |
| ETHIOPIA | Addis Ababa Fistula Hospital (AAFH) rehabilitation centre ^{6,49} | Passive | <p>A new development in the progress of the AAFH offers a treatment schedule prior to surgery and during recovery (lasting about three weeks) of psychosocial therapy and income-generation skills and educational services on topics such as reproductive health and literacy.</p> <p>There are also efforts to create awareness among the society about the problem through radio programs aired in cooperation with other NGOs. It also takes some former fistula patients for training to become nurse aids for the outreach centres. Currently, there are twenty former fistula patients who are taking training to be recruited in the outreach centres.</p> | | | |

¹ Active (facilitating education and vocational training opportunities, which were followed up and lead to an independent social reintegration) or passive programmes (where women are given training but are not followed up to ensure enhanced social functioning)

² Data from the Thematic Evaluation of National Programmes and UNFPA Experience in the Campaign to End Fistula. Assessment of national programmes. VOLUME II: HERA & ICRH / Final synthesis report / March 2010.

6.4.1 FORWARD Nigeria (23,29,95)

The Foundation for Women’s Health Research and Development (FORWARD) project was set up just over ten years ago by Dr. Rahmat Mohammad to improve the health and socio-economic status of women with obstetric fistula so as to meet the objective of rehabilitating and reintegrating survivors into their families and communities. It takes a holistic approach to managing fistula survivors by not only providing surgical repair with social and psychological rehabilitation, but also through fostering a culture of community participation.

The key components of its reintegration strategy take place at its residential rehabilitation centre, to which women are referred through recommendations from local government officers, community leaders, community-based women’s organizations, individuals, and previous clients.

Several interventions are coordinated and managed during the 6–10-month stay. Central to it all is surgical treatment (and appropriate rehabilitation, preoperative and postoperative nursing care) as all intake interviews cite that this is the one thing that the women want done as quickly as possible so that she feels normal again. Surgery aims to be completed within three months, if possible, to give the girl or woman hope as soon as possible that she will be “normal” again. This helps in promoting a perception whereby she does not see herself as a patient, victim, or inmate. This also reduces the length of time she is seen as “ill” by her family.

An intensive counselling process is in place to aid physical and psychosocial rehabilitation so that girls and women understand how the VVF occurred and what to do to prevent a recurrence. In addition, peer-group counselling also plays a part in the whole residential process. In this setting, women create ties with other women like themselves in an atmosphere of support and learning that facilitates group discussion. Innovatively, counselling programmes are also provided for the women’s family members who are tracked down as soon as she is registered with the centre and invited to visit. Establishing this link between FORWARD and the communities also helps immensely during the follow-up component of the project.

Girls in FORWARD Nigeria project after a literacy class.
(Courtesy Rahmat Mohammed)



A low socioeconomic status and lack of education have been identified as the major causes of obstetric fistula in the project area. In order to address these, literacy, numeracy and vocational training are provided, along with numerous income-generating activities like cap- and soap-making, and animal husbandry. Small business management principles are also taught to help clients develop the skills necessary to manage their own businesses when they return to their villages. A graduation ceremony takes place after a median stay of 10 months at the centre, where the women's families as well as community leaders and government functionaries are invited to meet the women who are transformed from outcasts into empowered literate individuals. Upon leaving the centre, FORWARD provides seed money amounting to approximately \$40 and/or specific quantities of knitting, sewing, or crochet materials, animals or other raw materials for activities such as peanut-oil processing and snack production. Women pay back in installments with 0% interest, which is collected during outreach visits or when the women come to visit the centre.

There is then subsequent reintegration of women into their communities with 12-months of outreach follow-up to monitor their reintegration into their communities, their general well-being and their income-generating activities. The aftercare visits by an outreach worker helps to educate women on how to be better able to resist being forced into positions where their new skills and empowerment would be stifled. The outreach worker also provides technical assistance so they can continue with their income-generating activities, help pass their skills on to other women in their village, and form community-based organizations that can be registered as a cooperatives. Women are reported to return to their villages with a higher status than when they left. These women are now referred to as “Malama (teacher) educated in Dambatta.” Some clients have been so empowered that they were able to “renegotiate” their marriages. In some cases the marriage was dissolved and they married men of their choice.

Rahmat Mohammad following up a FORWARD Nigeria graduate who has been trained by the project to become a teacher in her village.
(Courtesy Gloria Esegbona)



The initiative has recorded success because stakeholders and beneficiaries at all levels have been involved in its planning and implementation. Key components of its reintegration strategy take place at the community and political levels by using community advocacy and sensitization to raise awareness of reproductive health and rights, and the necessity of integrating women into mainstream community development programs. In addition, health committees have been established in the communities to promote reproductive health scaled up by the use of motivational mobilizers in the form of former fistula clients. Becoming a CFA who can discuss issues of overall growth and reproductive health helps them to reintegrate into the community. In addition FORWARD has worked in

close collaboration with ministries of health and social and women's affairs, local women's organizations, NGOs, and community-based organizations, which provide training for the women and help them launch their cooperatives and businesses.

Between November 1999 – March 2010, some of the notable results achieved by the rehabilitation programme include: 185 women were admitted to the residential centre for full surgical, social and psychological rehabilitation and all were successfully reintegrated; 41 behaviour change meetings were held in patients' communities; 247 follow-up visits were made to patients' homes; 30 community fistula advocates were trained in advocacy and awareness-raising. In addition over 450 women and girls have benefited directly and indirectly from the services of FORWARD Nigeria and over 800 have benefited from the preventive programmes.

6.4.2 Delta Survie, Mali (60,84,96,97,98)

Delta Survie pour femmes souffrant de fistules is an NGO which collaborates with the fistula centre at the Regional Hospital of Mopti, Sominé Dolo, to provide social and surgical recuperation services to women suffering from obstetric fistulas. Established in 2000 by Ibrahima Sankare as a transitional centre, Delta Survie found that the multiple surgeries usually needed to address fistula required a long convalescence, and that the marginalized social situation of many of the women called for a fresh set of skills, in order to build new lives after the medical situation had been addressed. They decided to join with the surgical and medical services being given by the hospital. A Canada Fund for Local Initiatives helped open an accommodation centre on hospital land. This includes two dormitories with 36 beds, a block of toilets, water pumps and a garden plot. The centre provides social support by providing women with a community of people that understand, and a place where they can live normally, eat, cook and talk with others, especially if they are alone. There is a lot of open space and women cook and spend much of their day outside, in the communal courtyard. The women see themselves as a community, they bond together to help each other recover, to mind each other's children, and to make food. Most women stay at the centre before and after undergoing surgery for their fistulas for a total of about three months: the recovery time required following treatment. However, women who need multiple operations may stay for longer.

Each year, the centre accommodates 80 to 120 women with fistulas. In 2007, a total of 126 women, instead of returning home after their surgery, decided to stay near the hospital for up to a year, to receive counselling, education and often, a second or third surgery. During a two-week visit in 2008, it was noted that 51 women were living there along with various family members (Connell). Women come from other Malian hospitals to recuperate, as well as from neighbouring countries like Ivory Coast. It also provides a permanent home for 20 to 40 women who have not been healed or cannot return to their village.

During their stay, Delta Survie promotes the social and economic reintegration of women by providing training in textile production, weaving, wet-clay chemical and vegetable dyeing (bogolan), sewing, market gardening, or soap-making which can be used in the future to help rebuild their lives and support their families. The other large communal training activity is making crafts (primarily jewelry) which are sold to tourists and international partners, with the profits shared among the women. The women create beaded jewelry, scarves and other intricate textiles and the

light, stationary work is seen as perfect for women in surgical recovery. Jewelry-making is voluntary but the woman must participate if she wants to make money. The centre serves as the workshop and storefront for the women's jewelry and textile business, with a jewelry boutique, adjacent to the centre, welcoming customers to "Boutique des Femmes Malades de Fistules" (Boutique of Women With Fistula Illness). In addition, life literacy classes are run by the NGO, Medecins du Monde, for eight months of the year in the local languages and in French.

Delta's national communications program also seeks to strip the veil away from fistula and define it as a treatable disease by encouraging women who have been healed to liaise with the community they come from – identifying and demystifying the affliction. These women are fully committed to Delta Survie because they feel they are indebted to the centre. Since 2007, the NGO has trained 20 fistula patients to speak about treatment and prevention in their communities. Incurable women are not trained as advocates but work is done to build their confidence so they can take responsibility for certain activities at the centre. In addition, they are funded to reintegrate back to their villages or a place of their preference in order to trade in a profession they have chosen to be trained in.

The centre is also involved in activities of prevention, screening and rehabilitation at the community level. This is done with intensive awareness raising sessions at the village level using the radio and television in collaboration with the administrative and political authorities in the region of Mopti. With financial and technical support from UNFPA, Canadian Cooperation, the program of the United Nations Volunteers and the French NGO, Bilou Toguna, it has been able to reach 399 villages. The goal after three years is to reach all 2,083 villages in the area.

N'Gouma and Ouro Ali
"to defeat the fistula
with us the obstacles"
(Courtesy Ibrahima Sankare – Delta
Survie)



The aim is that when women leave Delta, they have regained their dignity and self-confidence, and have a trade they can practise, and have acquired knowledge that they can share with the people of their village. However, it is recognized that there are challenges: the current structure is best suited for women whose stay at the hospital is three months or more, as high turnover makes it difficult to create ownership and maintain skills. In addition, bringing women together in one location poses the risk of ghettoization of the area, which may have a particular impact on women that remain at the centre for long periods of time. Sustainability, particularly financial, is also an issue compounded by the difficulty of finding a market for the centre's products. Lastly, proper evaluation of the project's impact is difficult as there is no current follow-up component after women return home.

N'Gouma and Ouro Ali
 “to defeat the fistula
 with us the obstacles”
 (Courtesy Ibrahima Sankare – Delta
 Survie)



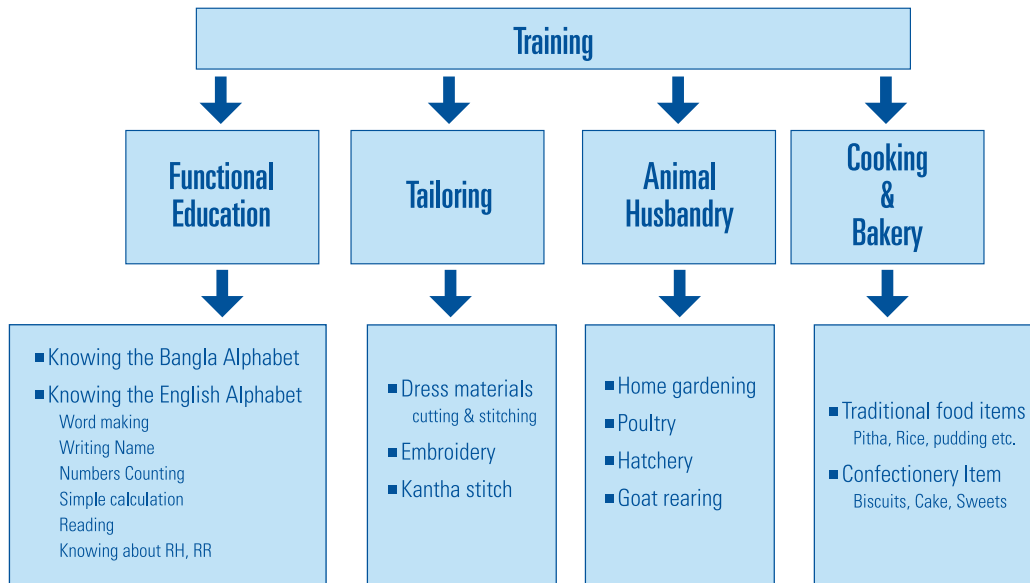
| | |
|--|----------------------------------|
| No of women hosted in rehabilitation centre | 1,146 |
| Francs given to women as rehabilitation funds | 8,000,000 CFA |
| Materials distributed to women | 10 sewing machines, two carts |
| Training given in: jewelry, soap, bogolan, dyeing, gardening, sewing, managing small and medium enterprises etc. | 677 |
| Members of village committees to monitor fistula | 490 trained in 70 villages |
| Number of people including administrative, political, and religious factions sensitized and informed about the fistula, its prevention and medical care and socio-economics in and outside of Mali | 310,451 |

6.4.3 Fistula Training and Rehabilitation Centre, Bangladesh ^(37,99)

The Fistula Training and Rehabilitation Centre, linked to the National Fistula Centre at Dhaka Medical College Hospital (DMCH), is managed by the national NGO, Bangladesh Women’s Health Coalition, and was established in 2006 with support from the UNFPA. It developed out of the recognition that some patients who were not fully cured and those awaiting surgery stayed in the hospital for very long periods of time. Informal education started for the women with the aid of a gynecologist and one volunteer. This initiative was greeted with such great enthusiasm that in 2005, the hospital authority provided, on request, an unused room to provide space for a livelihood and life-skills training programme.

Training Package

Includes 4 categories of livelihood training



Its goal is to empower the cured fistula patients to reintegrate and rehabilitate into society thereby improving their social, economic and psychological conditions. To this end, it aims to:

- Provide psychosocial counselling for confidence building, decision-making and mental recovery.
- Impart a need-based customized training in IGAs for economical solvency and self-reliance, and to assist cured fistula patients in restoring their social acceptance.
- Create a cadre of Community Fistula Advocates (CFA) for mass sensitization and community mobilization for eradication of obstetric fistula from the society.
- Create mass awareness in the community on the “Campaign to end obstetric fistula” in Bangladesh.

It employs both a residential- and community-based approach and its target beneficiaries are poor fistula patients who are divorced, separated, or deprived of family support. Fistula-treated patients who are willing to take IGA & vocational training or wait (for those fistula patients who are to undergo treatment from DMCH) are also selected. Once cured and patients have successfully completed the formal training workshop, they receive a certificate and are provided with training materials (e.g, sewing machines, animals, vegetable seeds, bakery items, etc.) with a one-off working capital grant.

It is the only initiative in the country that is strongly focused on rehabilitating cured fistula survivors in their own community, with a long-term vision of developing them as ambassadors in the community – as Community Fistula Advocates (CFA). Follow-up is provided to women when they return home to facilitate their reintegration into their families and communities. It is also a way to identify any vocational or literacy skills needing reinforcement, or any issues requiring additional support, such as counselling the family or community leaders to ensure they understand the importance of their women gaining access to credit and income-generating activities through the local agricultural

and social welfare offices. In addition, some former obstetric fistula clients are trained to become community fistula advocates (CFAs) so that as well as being taught in IGAs, they are also coached to become communicators, ambassadors, and peer educators, that carry out sensitization and health education on prevention, treatment, and also some limited patient referrals. In the future, there is a potential to build upon the CFAs to help them become the community-based trainers of newly repaired women.

Training in animal husbandry, Bangladesh.
(Courtesy Roushon Ara Begum, UNFPA.)



There are currently eight full-time and four part-time staff who manage the 28-bed capacity accommodation centre, three training rooms and the counselling and administrative rooms. Up until June 2009, 235 women have been rehabilitated. Although currently open exclusively to obstetric fistula patients, the fistula programme was exploring the possibility of referring obstetric fistula patients to centres that are receiving women victims of gender-based violence.

Performance of Centre from November, 2007 to July, 2009

| Description | Number |
|--|-------------|
| Fistula patients admitted at training & rehabilitation centre | 235 |
| Number of operated fistula patients at centre level | 215 |
| Re-admission/follow-up visit | 77 |
| Link-up with microcredit & micro-entrepreneurs | 80 |
| Link-up with different service centres | |
| ▪ Upazilla Agriculture Office | 56 |
| ▪ Upazilla Veterinary Office | 7 |
| ▪ Upazilla Health Complex | 149 |
| Four Categories of Training (Functional Education, Tailoring, Agriculture, Bakery) | As per need |

6.4.4 Dimol, Niger ^(10,7,87)

“To cure a woman, you must first treat her psychologically: you make her at ease with other women. She needs to socialize with other women especially if she has been isolated,” “(at Dimol) she is given a sheet, and bed and realizes her value. She cooks with other women.”

Salamatou Traoré, a nurse and midwife, founded Dimol, an NGO based in the capital of Niamey which addresses the health, social and long-term economic needs of Nigerien women who have suffered an obstetric fistula. Salamatou Traoré founded Dimol after finding that many women with fistula, even those successfully repaired, opted to reside near health facilities due to the exclusion from their communities. To relieve these centres and allow these women to become actresses of development, Dimol – a word meaning “dignity” in the local Peul language – was set up in 1998. It has a cyclic process of reintegration, beginning from where the woman is found (often places near health facilities where they have taken refuge away from stigmatization and marginalization) and ending in reintegration into their communities.

After much research to determine who the women were, why they were excluded and by whom, as well as what they needed to reintegrate into their community, a project was developed that included several components. The first phase comprised of interviews with fistula survivors to establish their origins, where fistula was contracted, history of the condition etc. If their fistula was unrepaired, women were then referred to a health care facility for treatment after which they receive counselling to educate them on the causes and consequences in order to prepare them for return to their communities. Dimol provides respite care before and after surgery, and trains women to bring knowledge of health and hygiene, plus income-generating skills such as soap-making, sewing and embroidery back to their villages.

A sum of around 25,000 FCFA (\$50) was given to women to carry out the income-generating activity she learned at the hospital with the help of partners such as UNICEF, and transportation costs were paid to the woman for her return home. After 12 months, the initial results from the project were disappointing, with nine out of 21 women that went through the programme reappearing at the hospital in Niamey. In response to these findings, another component was added to the project – accompanied reintegration. A team composed of a doctor, a social worker and a representative from Dimol accompanies the treated woman to her village. Because this involved additional costs, Dimol developed advocacy strategies to convince its partners, such as the network to eradicate fistula in Niger and the UNFPA, to join its new approach.

During the accompanied visit, the team conducts meetings with her husband, family, village leaders, community health care personnel, and any significant others on the nature of fistula, and instructions for postoperative care. The team also works with the woman and her family to plan for a return visit after six months of sexual abstinence, for a medical examination and to provide contraception for six months. Due to advocacy, caesareans are provided free to all women who have undergone fistula repair to ensure against recurrence of fistula. Dimol may also conduct follow-up missions to the village.

To foster reintegration within the community and prevent the woman from returning to the facility, various methods of communication such as video interviews with survivors and community sensitization campaigns are used. These help to educate players in the community on topics such as early marriage, the importance of antenatal care and skilled attendance at birth, schooling for young girls and the causes and consequences of obstetric fistula. Groups in the community such as fistula survivors, youth, women, spouses, neighbors are actively involved in these reintegration activities.

Some constraints have hindered the process, such as road impassability, women becoming pregnant again too early, and false information. However, overall, results have been positive. In 2004, none of the 59 women that benefited from accompanied reintegration have returned to the facility in Niamey. In total, up until 2005, 101 cured women were reintegrated due to community acceptance. The 62 who were unaccompanied home had nine had no recurrence.

Some lessons learned include: realizing that women do not want it known where they have been, such that Dimol uses a low-entry technique that is widely accepted in Niger. In addition, it has been found that some women do not want to leave the hospital after having stayed there for one time. The long stay had a negative effect on women: they lose their social references, feel safer in the hospital and organize their lives around it (receiving gifts, and engaging in prostitution, etc.)

6.4.5 Kissidougou Central Hospital, Guinea ^(100,101)

Since October 2005, Engender Health (EH) has supported Kissidougou District Hospital (KDH) in the forest region of Guinea to provide reintegration of fistula patients into their communities. KDH works closely with the UDC – (urban development commune, consisting of the mayor and his council) to improve community and local government involvement in reintegration of women living with obstetric fistula. The UDC provides funds to rent a waiting home for fistula patients, near the hospital, where they can wait for treatment and convalesce after surgery and this is where reintegration begins.

Patients come to the waiting home approximately two weeks before surgery for preparatory testing and receive physical and psychosocial support by being welcomed into a non-judgmental community of women with whom they can identify. Health education is also given where she learns about the causes of fistula, how long she must abstain from sexual activity after surgery, family planning, how to prevent re-injury and the need for caesarean section in subsequent pregnancies. During a woman's stay at the waiting home, a program officer provides an orientation to public speaking and interpersonal communication with additional guidance given to women who are skilled communicators. After returning to their communities, many of these women use social events, such as weddings, to raise community awareness about the causes of fistula, how to prevent fistula and the availability of treatment. From July 2008 through March 2010, 72 (53%) of 137 women who had stayed at the waiting home conducted at least one awareness session in their communities.

Funding is not currently available to support other types of skill-building or income-generating activities in the waiting home, even though it's recognized that such activities would further facilitate reintegration. The project instead plans to partner with community organizations and other elements of civil society to develop skill-building activities for patients.

Some patients face long recovery periods, while others are financially unable to go home and then return for their three-month postoperative check-up. In addition, it has been suggested that one should not assume that treated women would wish to return to their community of origin given the stigma. Therefore, the outcome of reintegration should be stated as "reintegration into social life" without defining a specific community. Thus, during 2007 and 2008, the UDC, in collaboration with the Ministry of Social Affairs and Women's Promotion, began implementing the intervention of social immersion with host families to support reintegration of fistula patients. In this process women are invited to spend one to three weeks right after their surgical repair socially immersed in host families who provide residences and support for them after surgery or between procedures. A waiting home coordinator identifies the families and arranges for patient placements. Several families near the repair facilities in Kissidougou and Labe kindly volunteered. Host families facilitate reintegration by providing transitional experiences that support women before they return home. Many women who have experienced marked social isolation, sometimes for years, and have undergone a profound emotional decline are said to find themselves suddenly in a supportive, caring environment and accepted by the community. They can once again participate in normal family activities such as cooking and attend social events like weddings to the extent to which is they are comfortable. Also, because the families make it possible for women to extend their stays at the fistula repair centre, women benefit from continued postoperative care. During the social immersion period, healed women conduct community awareness campaigns around social events (such as marriages and naming ceremonies). They also use rural radio to speak of their stories and communicate relevant messages to communities. The host family initiative began in March 2008 and since then, through to March 2010, 137 of 639 fistula care patients stayed with a host family.

Lessons learned from the social immersion approach:

1. Fistula survivors who participate in the social immersion program demonstrate improved confidence and regained self-esteem.
2. An effective fistula care program should go beyond urinary continence to address emotional and psychosocial "continence"

Social immersion in Guinea.
(Courtesy of Moustapha Diallo,
Engender Health.)



Her name is Fatoumata Lamarana Barry. She is 32 years old. She was married at 14 years old in a very remote village where tradition is the ultimate reference. She accepted the marriage in the name of tradition, so she found herself in a world of adults without any transition. This was catastrophic for her. Following a long (2 days) and hard labour, she lost her child and found she was unable to hold her urine. Shame engulfed her. She was abandoned by her husband. Her friends walked away from her and her family isolated her. She lived alone for 18 years. Then one day, she learned that she could be treated at the regional maternity of Labé. She went there and was treated successfully. Fatoumata Lamarana said: "Isolated for 18 years, I thought I had become an animal. I thought so even when I was healed. I recovered my entire health after my stay in the Bah's family".

Today, Fatoumata Lamarana is smiling again. Her friends celebrate the return of Fatoumata Lamarana Barry at her native village.

Social immersion in Guinea.
(Courtesy of Moustapha Diallo,
Engender Health.)



Mariama was married at 13 years; her father forced her to marry an old man who already had two wives. One year later, she found out, as a consequence of prolonged labour, that she had acquired an obstetric fistula. She was abandoned by her husband, her friends and even her family. For 10 years she was isolated and excluded from social events in the village. She lost her smile. She had a successful surgical repair at the regional hospital of Labe, but was still suffering from emotional decline. After one week of social immersion, Mariama has recovered her smile; she has been totally adopted by her host family as shown by this picture.

6.4.6 **Fistula Pre-repair Centre Model in Amhara Region, Ethiopia** (70,102)

In 2005, the Addis Ababa Fistula Hospital (AAFH) opened its first regional fistula repair hospital, the 44-bed Bahir Dar Hamlin Fistula Hospital (BDHFH), in the Amhara Region. To reach more women with fistula, 3 of the 179 health centres in the Amhara Region were identified to become pre-repair centres for the BDHFH. Centres are staffed by fistula mentors, who help identify potential fistula repair patients, screen women for fistula repair, provide rehabilitation and relevant pre-surgery treatment to patients (to enhance their psychological readiness and improve their health status), and support reintegration after surgery. Fistula mentors meet clients in the health centre waiting areas and conduct health education sessions on a wide variety of topics.

Once a woman reaches a pre-repair centre, she receives a package of essential services, including a physical examination to determine the cause of her incontinence. Women diagnosed with fistula of more than three months duration are referred to BDHFH for surgical repair. Women who have had fistula fewer than three months are catheterized, evaluated, and treated for incidental problems, discharged, and then scheduled to return for re-evaluation after the three-month period has elapsed; if necessary, the women are referred for surgery.

All women are counseled about what caused the fistula and what to do to prevent it from occurring again, family planning, HIV, and sexual relations after surgery. They are also counseled that they may not be cured with the first surgery. Patients generally stay at the centre for 5–14 days, depending on the degree of rehabilitation required to improve their readiness for surgery, as well as on the availability of a surgeon and a bed at BDHFH. Women are then transferred to BDHFH for repair and generally remain for 2–7 days prior to surgery and for two weeks after surgery. The BDHFH nursing staff report that women who have had care at the centre arrive at the hospital cleaner, educated about the procedures, healthier, and more psychologically prepared for surgery. Former patients who serve as nurse-aides also provide valuable psychological support.

When ready for discharge, the patient returns to the pre-repair centre for post-repair care (lasting from one day to one week). The patient is again counseled on family planning, HIV, future pregnancies. She is advised to wait two years before becoming pregnant again, to get early antenatal care, to deliver at a hospital, and the need to abstain from sex for three months. There is also provision of literacy training to the women, whilst they are recuperating from surgery. As most can't read or write they are provided with portable audio players to provide them instruction on safe motherhood and what they need to do to be ambassadors for safe motherhood in their villages.

A patient card is given to all women on discharge, indicating the outcome of her surgery. She is transported back to her community, where she is encouraged to become an advocate for fistula prevention and care. The mentor will visit her monthly for six months, then quarterly, to assess her physical status and social reintegration. The centre organizes transportation back to BDHFH for a routine six-month post-surgery check-up. As the centre is in a rural area, much closer to where the people live, postoperative follow-up is more likely to be achieved.

About two thirds of women come back for follow-up and have a structured questionnaire administered. This covers things specific to the surgery and the outcomes thereof, but also includes questions about whether they have regained normality in their life at home –with questions related to social interaction, working ability, marital status, sexual intercourse, menstruation and subsequent pregnancies.

A ten-point Likert scale is used to assess the overall impact of fistula repair on quality of life; women are asked to grade impact on a scale of: as much worse, worse, slightly worse, a little worse, no different, a little improved, slightly improved, moderately improved, greatly improved and completely cured. Results show that several have started to go to school in their villages after the introduction to education that they received as part of the programme.

Before the operation, almost all were not working, but after the operation, 68% were back at work. If they weren't, it was largely because they weren't completely dry, or were waiting for permission from the hospital to return to work. Before the operation, only 15% were attending the market, social gatherings, church or mosque, increasing to 78.8% after, but only if completely cured. There have been some remarriages, but not many. If they were cured, 41% had resumed sexual relations, falling to just 21% if they still had some degree of incontinence, even if the fistula was closed. On a scale of 1 to 10, rating the impact the fistula repair had on improving their quality of life, the vast majority scored 8-10 (i.e., at least improved and maximum – completely improved).

When patients become pregnant again, they are encouraged to return to the hospital and wait for a safe (caesarean) delivery –currently thought to be the safest mode of delivery following fistula repair. The pregnant ladies in the ward, and those who have delivered, come with their babies to the education classes and have group discussions with the fistula patients about the possibilities of coming back for their next pregnancy and how to ensure they get a live child. The hospital has had nearly 200 deliveries over the last few years and there have been no fistula recurrences. During the same time span, nearly 40 women have returned after trying to have their babies back in their villages. All the women lost the babies and all had a repeat fistula.

In summary between July 2006 and September 2009, a total of 811 women were screened for fistula at the three pre-repair units and the same patterns have recurred. If they are cured (i.e. dry), they return back to their normal lives, if they are not, then they have problems.

6.4.7 Trampled Rose ⁽⁸⁵⁾

The Trampled Rose Centre is a non-governmental, non-profit organization that was established in June 2005 to support women with obstetric fistula. It started as a help for the Hamlin Fistula Hospital but they believed their training gives the women “unrealistic hope for the future” so the centre now works independently with the help of the local regions who love the program. The centre functions by using key informants with proper knowledge of areas where early marriage is rampant to identify and locate women with fistula. They are then provided with free vehicle transportation to the centre where they are provided with all the available pre-treatment psychosocial therapies before being admitted for medical treatment to an assigned private hospital.

Once the fistula is treated, the women are relocated back to the centre and offered income-generating skills training and rehabilitation programs. Trampled Rose focuses on literacy and math skills. The women are quickly encouraged to learn how to read 180 words on their first week with the centre so they are quickly encouraged. They then learn at least three sellable skills depending upon the area they are from (the women themselves choose what they want to learn.) The centre’s goal is literacy and a business plan they can implement when they leave. To date, 87 women have graduated from the program. The follow-up has been weak but the centre has learned some hard lessons and is writing the follow-up into the next project.

The program comprises three very intense months and the centre can handle 40 women in each group. It started with a year-long program but after that much time, the women did not want to return home (the Ethiopian government strongly prefers they return home). The centre works with the Amhara Development Association to find women in the worst cases. Presently the centre is facilitating interest-free microloans to the treated and rehabilitated patients so that they can become economically independent and reintegrate more successfully back into the community as productive citizens.

Specifically the program targets incurable women but the centre also helps those that have been cured but have trouble living on their own because the community is not as welcoming as may have been expected. The centre also provides surgeries if it comes across women who have been labelled incurable but actually have a chance to be cured. The number one graduate from their last group was a woman who had been leaking for 13 years after her last surgery. She is now cured, literate (second grade level is the goal) and is starting a business selling sambusa and taking in ironing for her village.

6.5 Challenges and Considerations in Social Reintegration

Certain aspects of the interventions used in social reintegration may unwittingly cause social disintegration rather than reintegration by inadvertently exacerbating the situation of the woman, despite best intentions.

6.5.1 Incurable women and unsuccessful operations

The term “fistula survivor” is commonly used. However, during the national or international strategies of how to end fistula, the true fistula survivors are usually forgotten (103). The incurable women whose fistulas are too complex to repair are the women who really survive the effects of fistula. The challenges they face are easily gauged from the numerous reports and studies looking at women’s experiences of having fistula (5,6,7,11-17,50-53,66). Their permanent incontinence, and the odour and discomfort it produces cause social outcasts. The stigma and shame lead to self-isolation in their homes and being banned from social activities, such as jobs or socially mandated roles such as mother and wife. They may then face an escalation of community mistreatment after unsuccessful repair attempts.

Without being cured, they commonly spend the remaining years of their lives in shame and isolation, literally waiting to die. In the true definition of the word, they survive, but they need a lot of support to rebuild their lives. This is a challenge, as many see reintegration as returning women to their communities, which often is not easy to achieve with these women, due to the medical, logistical, ethical and social challenges that are posed (1,31,41,93). So where do they go? What happens to them? What services do they need?

Some recommend some form of a urinary diversion operation. However, while it would seem logical that with a diversion, they may be better off, there is little objective evidence on which to base decisions on the practicality of performing urinary diversion, as all the operations have implications for social reintegration (104,105).

The ileal conduit, for instance, involves wearing a urostomy bag for life. Women may be completely dry but because bags may be difficult to obtain in a developing-country setting and can be only be obtained from the hospital, women cannot return to their homes in remote areas. In Addis, this problem has been partly overcome by providing a separate village not far from the hospital where they can live. However, “whether they are entirely happy with this situation is an open question.” (106) Now that a number of outreach centres have been set up in and around Addis, it may be possible for some patients to return home and obtain supplies of bags locally (70,102).

In the Mitrofanoff procedure, self-catheterization is needed. Although women with such an operation can have a good quality of life, there is a significant incidence of problems with stenosis and difficult catheterization which can be disastrous if the woman is away from skilled help. Some women may prefer to continue to leak, rather than having to be dependent on a medical facility for

the rest of their lives. For instance, in one study a woman had urinary retention and despite being dry with continuing intermittent catheterization, claimed that she had been better off being continually incontinent with her VVF, rather than self-catheterizing but being dry (54).

More commonly the Mainz II pouch, where urine is diverted into the large intestine, is used as it is said to make the woman dry by day and often at night (107). However, while the quality of life may be good, there is risk of morbidity such as ureteral stenosis, increased risk of secondary malignancy, and chronic pyelonephritis leading to long-term renal failure. The latter being the cause of 2 deaths in a series of 37 women offered diversion in East Africa (108). As a result, women may be unable to reintegrate into their communities as they have to live close to the hospital to ensure that they receive adequate follow-up to detect any short- and long-term complications which may arise.

This is difficult to achieve for the significant number of women with fistula, especially those from the rural areas; many do not attend. In addition, as the woman has to pass urine through the rectum for the rest of her life this may not be socially acceptable in some communities and seen merely as moving the fistula to another part of the body. The end result being that the woman may be even more stigmatized in the local culture than the original injury (109)! One woman described being offered a diversion as “now I will be like the chicken – urinating and shitting from the same place!” (103)

These issues require that women be counselled extensively before they are offered any form of irreversible diversion which may be acceptable to the surgeon but not the woman, especially if it impedes her social reintegration (106). Moreover, it seems there are usually no specific or standardized criteria to decide who to offer diversion – decisions being based on experience (108). It also needs to be clear that the woman is truly inoperable and that she understands the implication of what having the operation will do to her social well-being. Some women prefer to remain incontinent once they are fully informed, especially once they are aware of the importance of follow-up and what impact not returning can have on their long-term health (103).

Incurable cases are said to be the ones most in need of intensified physical, psychological and vocational capacity building to enhance their return to their community and help them become economically stable (1,29,41,101,103,110). To help with this, the Addis Ababa Fistula Hospital, in 2000, created the Desta Mender “self-help” village, in recognition that not all women will be able to reintegrate themselves into the communities they came from. In the village, there is provision of long-term accommodation for around 50 long-term residents.

Reintegration and rehabilitation are through training activities such as poultry care, hospitality and farming, where women can grow vegetables and care for livestock. The farm is an integral part of the rehabilitation process, encouraging women to engage in productive activities and thereby regain their sense of self-worth. In addition, most of the women there attend school and are educated in microbusiness (e.g. selling their produce at the local markets). Some women have established small, successful businesses that have enabled them to move out of Desta Mender to nearby towns and return to receive medical care or visit friends.

In addition, the opening of several mini-hospitals in rural areas means that some women can now move to live closer to family and visit a mini-hospital for medical supplies and checkups. This way, the hospital seeks to help even the most severely injured women to “become citizens of the world again” and where possible, living independently as close as possible to their own community (111).

CASE: Fistula Foundation Nigeria–Reintegrating the women with an incurable fistula ^(23,110)

Fistula Foundation Nigeria (FFNIG) is an NGO based in Kano Northern Nigeria with expertise in social reintegration activities and advocacy. Founded by Musa Isa who has worked since 1987 with women with fistula, FFNIG complements the existing medical and surgical work being done in Northern Nigeria by Professor Kees Waaldijk and his team in various hospitals, by providing women with fistula the necessary psychological and other support required to take the steps to return to their communities.

Women who present to the various hospitals, and the Kwalli rehabilitation centre, are clerked in and counselled to identify their needs, such as psychosocial counselling, rehabilitation services, and empowerment training by vocational skills acquisition (sewing, soap making, agriculture etc). For most, the only thing they request, in order to return home, is surgical intervention which is arranged as soon as possible. Continuous daily counselling also identifies those left in a bad social situation such as divorce, and rejection, or suffering from psychiatric conditions because of their fistula status. The scope of its reintegration activities also extends to community mobilization and behaviour change communication activities to prevent further cases from developing.

Central to these activities is the training of women with obstetric fistula, to become community educators so that they may educate the community on the causes of obstetric fistula, to reduce stigmatization and all forms of isolation from family and the community, and mobilize the community, especially the men and community leaders to seek surgical care and reintegration for their women. There is also extensive community outreach with tracing of relatives, escorting the women back home and facilitated reunification. In most cases, these women are reintegrated with their communities. In other cases, especially where repairs are not completely effective, they need to develop new community systems to cope with the problem.

The Fistula Foundation Nigeria is unique, in that it specifically targets and helps women that are incurable, and has built up specialist expertise in reintegrating these women back into their own communities. It has an up-to-date record of irreparable women in Kano, Katsina, Zaria and Abakaliki states.

To investigate the correlation and impact of an incurable obstetric fistula on a woman’s psychosocial well-being, a sub-audit was done of 182 of the 582 women on its database in the state of Kano. The ages ranged from 17 to 68 years, with most of them primiparous (76%). Women had been leaking anywhere from nine months to 48 years and had presented for multiple repairs in bid to cure their incontinence. Because of their leaking, their families and communities viewed them as disabled and defective, which often resulted in divorce. (**Table 5**)

The data also suggest the need to look at what makes a woman incurable, as what is deemed impossible to repair in one surgeon's hands may not be so in another. And the wrong label of incurability exposes women to the risk of invasive procedures such as urinary diversion which may serve to disintegrate rather than reintegrate as stated above. In this series two women who were given a diagnosis of incurability were operated on by a master fistula surgeon and subsequently made continent. However, they still needed intensive reintegration work due to the length of time that they were stigmatized for (5 and 12 years, respectively).

Many women were found to have had an incurable fistula for years and this was been found to be a function of health providers' unwillingness to definitively tell them of their incurable status. This may be partly because some feel that perhaps the women maybe incurable in their hands but not in others. There were reports of women who were told they were incurable only to be cured after many years by skilled master surgeons. Others because there is no formal definition of what makes a woman incurable. As a result many women live in or around the hospital surroundings in the hope that they may one day meet a cure, exposing them to the risks of multiple repair attempts and the law of diminishing returns in achieving a successful repair (63). The length of time they then spend away from their communities poses a real challenge to their reintegration and even to their psychological status. Some were desperate when the irreparable nature of their condition became apparent with over 50% (118) of the women diagnosed with depression. One woman was severely depressed because her mother, who also had an incurable fistula, had died from it. She, along with four others, were in psychiatric institutions.

In some cases, women are reintegrated with their communities and back into their homes with facilitation by the FFNIG. This was found to be easier if they had previous living children – 11 out of 15 women with living children still living with their husbands. In addition, the few women who were educated from primary school level and above (4 women) were also living at home. In most cases however, women needed to develop new community systems to cope with the problem and chief among these were training in income-generating skills.

Since 2002, 136 irreparable fistula women have been trained in intensive skills acquisitions in different trades, with the aid of grants from the Irish Government and Australian High Commission in 2010. In addition, 200 cured women have been given skills acquisition materials after completing an intensive two-week training. A total of 78 obstetric fistula women who were divorced have reconciled with their husbands after counselling and visits to their home communities. Eighteen fistula women who had psychiatric problems are doing well after being taken to receive care at the local psychiatric hospital although four are still currently in hospital.

Another new initiative called the Jika pad (Jika means 'to soak' in the local language Hausa) has been developed by Dr. Esegbona to help women live and socialize despite being incontinent. Based on work with the incurable women in the FFNIG network, as well as on questioning as part of the audit, the biggest challenge facing most women was how to keep themselves dry so that they could undertake social activities.

All incontinent women were using self-made pads from rags (“rugs”), towels and wrappers which they wrapped/rolled into a bundle, and placed between their legs and held in place with knickers or a plastic sheet. Pad changes ranged from 4 times (23 women) to 10-12 times (112 women) per day. The worst problem with the pads for most women was the smell. Close to 90% (175 women) cited having to spend more than 40% of their daily income and 1-2 hours a day on washing the pads in order to have enough for the following day, and to be able to remove the smell from them. Substances like bleach were used daily to help with this problem but this was cited to cause rashes and infections on their skins and thighs (155 women) because it hardened the rags; making them scratchy when they walked.

Another way to cope with the leakage was to drink less so that they will urinate less often (132). Controlling the urine was worse at night because the urge to urinate came more frequently, and the leak would rush to the woman’s back (98 women), causing rashes.

The reusable Jika pad is made of 3 layers – a bottom waterproof layer topped by an absorbent antibacterial non-odour retaining core. The top layer is a soft material that wicks the moisture away from the woman’s skin so that she feels dry and less prone to rashes. Work is underway to supply these reusable pads to all women with an incurable fistula in the developing world, and to use them as a meaningful tool in reintegration by teaching incurable women how to produce and market them not just as an incontinence product to other women with fistula waiting surgery, but also as menstrual pads.

The Jika pad



Women in Delta Survie Reintegration centre, Mali with Jika pads



TABLE 5 The Socio-demographics of 182 Women with an Incurable Fistula in Northern Nigeria

| | | |
|---|---------------------------------|-----|
| Parity | Nil | 155 |
| | One | 10 |
| | Two | 7 |
| | Three | 5 |
| | Four | 3 |
| | Five | 1 |
| Duration of fistula | Six | 1 |
| | 1-5 years | 17 |
| | 6-10 years | 39 |
| | 11– 20 years | 96 |
| | 21-40 years | 25 |
| Number of attempts at repair | > 41 years | 5 |
| | Two attempts | 58 |
| | Three attempts | 54 |
| | Four attempts | 42 |
| | Five Attempts | 17 |
| | 6-8 attempts | 10 |
| Marital status | 14 attempts | 1 |
| | Divorced | 166 |
| | Married | 10 |
| | Remarried | 3 |
| Residence | Separated | 3 |
| | Living in hospital/surroundings | 131 |
| | Living alone | 33 |
| | Living at home | 17 |
| Source of support | Living with parents | 1 |
| | Aggressive begging | 133 |
| | Remarried | 2 |
| | Food selling | 17 |
| | Empowered by FFN | 3 |
| | Nanny | 10 |
| | Selling second hand clothes | 2 |
| | Civil Servant | 2 |
| | Parents | 1 |
| | Knitting | 2 |
| | Clinical support worker | 2 |
| | Housemaid | 3 |
| Petty trading | 4 | |
| In psychiatric hospital | 1 | |
| Reasons given for psychological disturbance | Incontinence | 141 |
| | Bahanya | 98 |
| | Thinking about the cause | 67 |
| | Stigma/rejection by family | 171 |
| | “Doctors don’t tell diagnosis” | 45 |
| No more help | 158 | |

6.5.2 Family planning

The fistula patient is frequently cited as young women or adolescent girls who have developed fistula during the first pregnancy and have had their sexual health needs and basic health rights transcended (6).⁶ As such, it has been suggested that family planning be put in place as part of a reintegration package to help avoid the health effects of early childbearing until the woman is fully healed or to stop childbearing altogether if they so desire (1).

However, care should be taken not to push family planning to the extent that disintegration from her community occurs, as she may not desire family planning if her only pregnancy resulted in the fistula and a stillborn child, and her best hope of being accepted is to bear children again. Studies showing that an overwhelming majority of women are in their childbearing years and have experienced a stillbirth (up to 98% in some surveys) usually in their first pregnancy and then may experience secondary sub-fertility (54,65,59). Such childlessness has a major social impact in societies where a woman's status is largely determined by her reproductive capacity (18). In many African communities, a childless woman is unable to attain adult status, affecting their confidence, dignity and mental well-being (3). As such, for most rural women, sex and childbearing is a means of social survival (4). It is reasonable to expect therefore, that an overwhelming proportion of women will want to get pregnant soon, since many studies show that family life is the most important factor for attaining social status.

One study for instance, found that many women experienced the fistula as a direct assault on their ability to fulfill social expectations of them as women, wives and mothers (55). In another, 32% of the women stated that they desired more children (66). It is also relevant that in the same study, none of the women, with three or more children before developing a fistula, were divorced by their husbands. Studies have also shown that childlessness is one of the major reasons for divorce and that women are blamed for being childless in most cases. This is in line with another study where to be married was the wish for all, especially if they were childless, as with marriage children will come reduction in mockery and rejection and confirmation of their social status (50). In another in which midwives administered structured questionnaires to samples of women living with fistula or with fistula repaired, almost half of the 82 women studied wanted another baby in the future; 48% of them within the next two years (53). Moreover, women in Mozambique spoke of great pressure to become pregnant again after surgical treatment (6). Even with an incurable fistula, a woman still wants more children—11 women in one study conceived again, even whilst still leaking, in a bid to stay married (110). In another report, a 32-year-old woman who had lived with an irreparable urinary fistula for 15 years, after being told about the medical complexities of her condition, proclaimed that her first concern was whether she could get pregnant (105).

On the other hand, family planning may have a role since many patients suffer from fistula recurrences. For instance, during the UNFPA fistula fortnight in Nigeria, close to 50% of the women treated were repeat cases (101). Women express concern about conceiving again because of fears the condition might reoccur (50). Additionally, it has been noted that the policies and programs addressing fistula need to expand beyond the widely held assumption that fistula predominantly affects very young women on their first pregnancy. As studies have shown how fistula can affect women who have had “normal” deliveries before (14).

One study was conducted to understand the dimensions of fistula and its related social vulnerability through the experiences and views of girls and women living with fistula. The study found that it affects girls and women, not just during the first pregnancy but in later pregnancies as well; with fistula observed in about half of the women in their second or higher pregnancy (11). The median age at which women in the study developed a fistula was 23 years old and fewer than half of the women were 19 or younger when the fistula occurred. Similar findings have been found elsewhere, such as in a retrospective cross-sectional study comparing the characteristics of 259 women with obstetric fistula (80). In this study, the median age at marriage (18 years) and fistula development (22 years) was older than usually found. In addition, though 49.0% were primiparous, 27.6% had delivered four or more children. It has been noted however, that many of these multiparous women may have no live children in some studies, due to a poor obstetric history consisting of several infant and child deaths culminating in a stillbirth and a fistula (69,110).

Therefore, family planning needs to be considered carefully, and counselling becomes very important to understand what the woman's needs and desires are. It has been made implicit in several reports that the wishes of women—a return to fertility as desired and a safe future delivery as required—are paramount in determining the success of the woman's reintegration (30,42). Especially as what constitutes family planning is not just contraceptive management but also involves fertility preservation, and management of future pregnancies (112). Current efforts, such as that by the Fistula Care Project, emphasize counselling of the individual treated woman from two perspectives: to enable women and couples to delay first births to help prevent fistula, and to help women and couples achieve a successful pregnancy post-repair by allowing the woman time to heal (113).

6.5.3 Follow-up

In order to determine the extent to which a woman treated for fistula has been reintegrated back into social life, the importance of follow-up at the community level has been stressed (93,101). However, follow-up has been indicated as a real challenge (1), as many programmes labelled as reintegration are actually reinsertion programs as defined in other fields (39), given their short-term nature and focus ranging from a few weeks to months following repair. However, this is generally inadequate to draw conclusions about things which aid her reintegration, such as continence and changes in her social situation, such as marriage and fertility rates and psychological recovery (80). Even the follow-up of patients after fistula surgery and support to their reintegration in the community has not been sufficiently addressed by the Campaign to End Fistula (37).

Follow-up is usually hampered by several things, including the fact that the taboos surrounding fistula make it very difficult for many girls and women, healed or not, to return home and for follow-up information to be gathered (1). Then there is the fact women usually live in rural remote areas far from the centres treating them (4). As such, women may not practically be able to travel the hundreds of kilometres for a check-up, as transport is often difficult and the associated costs mitigate against return to hospital. In recognition of this, several satellite centres have been opened in the rural areas where women live, like the Bahardir Hospital in Northern Ethiopia, so that postoperative follow-up is more likely to be achieved (54). The hospital also provides reimbursement of transport costs and

additional expenses which may also act as further incentive. Nevertheless, it should be recognized that their follow-up rate is only 62%, and it is women with residual symptoms at the time of discharge that are twice as likely to attend for follow-up as those free from symptoms.

The advantage of having a follow-up as a key component of a social reintegration strategy is that it enables several things. Firstly, it enables monitoring and evaluation of centres to elucidate the determinants and correlates of success and failure, including the strategies women use to reintegrate. These will help one to understand the impact of any strategy so that subsequent improvements and adjustments may be carried out to programmatic design (6,88,109,112). This also ensures that meaningful patient-oriented indicators are gathered to determine the success of reintegration rather than just the organizationally focused ones (**Table 1**) (e.g. the number of organizations providing reintegration services) (101). Some reintegration programmes that have follow-up as a key component like DIMOL and FORWARD have established monitoring and evaluation systems designed to follow women with fistula who are repaired. Assisting with her reintegration and checking health, reproductive, demographic, and socioeconomic status on a three- to six-month basis for at least a year. This helps circumvent the situation where women fail to come for follow-up appointments due to poverty and distance. This allows them understand the issues women face when returning to their communities so that they can learn lessons that better prepare other women for reintegration. The system also helps identify those women who were not successfully repaired so that they can receive targeted help.

Then there is the fact that though the wealth of evidence points to the surgical repair being the biggest factor in ensuring successful reintegration happens, how strong this evidence is, is hampered by inadequate long-term postoperative evaluations. A holistic reintegration programme with adequate follow-up confers the advantage of making clinical research more robust. Studies have noted their limitations in defining the long-term success of surgical operations due to missing data for many variables in the clinical database (80,114). Much of what is available have been acquired from informal studies, case reports, and on-the-ground experience, gained in the few days and weeks after repair rather than from well-designed clinical studies.

Follow-up as part of a reintegration package enables one to draw conclusions about specific questions, such as the evaluation of specific repair techniques, the obstetric outcomes in patients who become pregnant after previous fistula surgery, and an understanding of persistent incontinence after successful fistula closure (57,81). Of course, long-term follow-up is needed to assess the risk of diversion surgery (104-106,108,109). This will then provide a continuous quality improvement with the goal of optimizing the care delivered to women (112,115). There are of course resource implications (human and financial) of such follow-up for a repair facility. Many are now recognizing the importance of partnering with NGOs and civil society organizations to track down women and ensure that women and girls treated for fistula are linked with much-needed social support services.

6.5.4 Resources and capacity

A comprehensive package of reintegration with physical, psychosocial and economic support and then subsequent follow-up does not come cheap. Some of the reintegration programmes, thought to be good examples, such as the Bangladesh programme, raises fears about sustainability or replicability because of the expense. Although it was noted it could help guide less costly community-based models (37). For instance, the programme can host 30 women but some stay for long periods due to delays waiting for surgery and for medical pre-operative tests, all of which add to the cost of services. In FORWARD, the cost of the reintegration approach is \$2,300 for a 10 months' stay at the centre, an additional \$340 is needed for 12 months of follow-up and reintegration (29). However, it was felt that with adjustments, it could have the potential for replication both in a facility-based and in a community-based context.

The sheer number of fistula cases also means that to offer a full package of physical, psychological and socioeconomic interventions to every woman may be prohibitive. Demand for services maybe exceeding the program's capacity, as seen in Guinea, with space at the waiting home limited and needing to be expanded (100). Furthermore, centres that offer fistula repair carry an enormous case load and struggle to meet the overwhelming demand for even just clinical care. As such they may not have the time or be well-equipped to gather information from women on their psychosocial needs as this may place too great a burden on the staff in the facility and compromise regular surgical and/or medical care (6). Sustainability is also a challenge, because to provide reintegration services requires thought about strengthening capacity and introducing training to ensure that, over time, staff have the ability to provide services, like counseling, regularly. Clearly the issue is beyond the carrying capacity of the repair facility/hospital and for this reason, it has been suggested that implementation of reintegration efforts be done by creating linkages between repair centres and existing NGOs or organizations already working with women or in poverty reduction (101). Such linkages will facilitate the collection and reporting of information on treated women that have returned to the community.

Another way forward is that as has been suggested with traumatic fistulas (116), a Minimum Initial Service Package, or the MISP is used. The MISP is not just about kits of equipment and supplies but a coordinated set of activities executed by trained staff to respond to the reproductive health needs of populations in the early phase of a refugee situation. Similarly, with adjustments there could be a MISP developed for fistula. This could take the form of counselling as the bare minimum to understand women's needs in the reintegration process, with more tailored interventions being given to women coping with chronic incontinence and ostracized for a long time, or the incurable woman.

6.5.5 Who to reintegrate

“In all too many cases, ... discussion of social development is ... phrased in terms of integrating those with nothing into the mainstream, as though the groups defined as excluded are surviving in a virtual vacuum...” (39)

It has been acknowledged that there may be ethical dilemmas in providing materials or financial support to individual women with fistula in poor communities rather than as part of a community approach (39,42). Though there is no denying that for many, their social vulnerabilities are rooted in poverty, illiteracy and gender discrimination which may occur alone or in combination, they generally have this in common with all women within their often marginalized communities. As such, just targeting them with help can create significant tensions in their community. Instead of producing the intended reintegration, the gifts or cash provided can create struggle over resources which can affect family and community acceptance as observed in other fields (39). Linking up with poverty-reduction programmes may be a better way forward, by creating linkages with existing NGOs that provide community-level programs (29,101).

The challenges of reintegration into the same social regimes has also been highlighted (49) as one should not assume that treated women will wish to return to their community of origin even if healed because of long-standing stigma and ostracization (44). In addition, though some women may be desperate to return to their communities and re-establish their original life, they may feel the best survival option is to stay close to the hospital. In recognition of this, places like the AAFH have established satellite mini-fistula hospitals across the different regions of the country to provide immediate health services to returning patients who choose to reintegrate back into their village (49). Thus, it has been said that the outcome of reintegration should be stated as “reintegration into social life” without defining a specific community (101).

Another important consideration is that though community advocacy and sensitization may alleviate the stigma and taboos surrounding the causes and consequences of fistula, women may not want it known that they have had a fistula, even if cured, preferring to slip quietly back into their previous lives. Perhaps because people may not believe they have been healed (2). “The woman said that some people ridiculed her by likening a bladder to a gourd and saying “a cloth can be mended but not a gourd.” As a result of this, Dimol uses the low-entry technique, having learnt from experience that women do not want it known where they have been (10). It also follows then that women may not want to publicize that they have had a fistula and advocate about community awareness.

6.6 Conclusions

The social reintegration of women with fistula represents a crucial process for their return into their families and communities. However, what reintegration actually means and what interventions are appropriate are best based on an understanding of the concrete needs identified by the individual woman. As women, whilst sharing a number of common experiences, they differ in their varying need for family and social support, livelihood and income generation. It is not always the case that they are abandoned by their husbands or are cut off from family, friends and daily activities, and live a life of isolation and destitution. And what an individual woman requires to return home is relative to her situational context, such as the length of time she has lived with the fistula before it is repaired. The frequent lag of time between surgery and reintegration has negative consequences for social reintegration, as women frequently remain away from their marital homes and continue to be perceived as outcasts. It also depends on to what extent her fistula repair was successful and thus, her level of continence, her ability to have sexual relations and her fertility.

Often getting her repaired as soon as possible so that she is continent is what a woman wants and is sufficient to enable her to reintegrate back into her community, though little information is available on how they achieved this. However, some women may require a triangulation of interventions, supporting health, economic independence and nullifying the psychosocial consequences of stigma that may serve to keep women isolated even once their physical condition has improved. Providing such a holistic package is resource-dependent and perhaps defining a minimum package of services, including counselling, will help to identify women in need of more targeted comprehensive interventions. Especially women who are not healed, despite surgical efforts, those who have no children, and those who have lived with fistula for a long period of time.

The importance of dedicated fistula repair centres to aid women's reintegration fulfills several aims including – providing a place for repair, a dedicated space for the women to recuperate and develop peer support, and the time to introduce her to desired reintegration services. However, often reintegration is beyond the carrying capacity of the repair centre and therefore linkages with other appropriate support agencies and NGOs, especially at the community level, may help. Such community participation goes a long way to breaking down myths that prevent reintegration. In addition, the work of CFAs to provide community-level education and peer support is a very effective method to reduce fistula occurrence and recurrence as they can educate, advise and act as role models to other women.

Many of these key issues emphasize the importance of follow-up of the post-surgical improvement in the quality of life of girls and women who have returned home. However, this is a challenge due to the expense and logistics of getting specialized staff. Evaluation of reintegration programmes are mostly confined to short-term retrospective assessments of lessons learned and best practices. There is a need for evidence about programmes that improve long-term reintegration, including the determinants and correlates of success and failure of interventions including surgery and how reintegration is linked to improving women's and communities' understanding of women's health issues. This will bring us closer to ensuring that those who are affected by fistula have the best possible chance of rebuilding their lives. Hopefully large studies such as that by John Hopkins will start to shed light on these and other questions.

6.7 Recommendations

All recommendations are based on articles with level of evidence 3 or 4. Hence all recommendations are Grade C or D.

1. Social reintegration should be seen as the process by which women with obstetric fistula are helped to overcome physical, psychological, and socioeconomic challenges, freely identified by themselves. In order that their level of social functioning in communities and social networks of their choosing is enhanced, such that the risk that they will present with another fistula is minimized. (C)
2. Social reintegration should be seen as a series of interventions, regardless of who performs them, that focuses on making the woman part of her social fabric again, and commences from the time leaking of urine becomes manifest. (D)
3. The aim of social reintegration should be to break the fistula recurrence/occurrence cycle, in which the woman's physical state is inextricably connected to her mental state and her socio-economic situation. (D)
4. Early successful surgical repair or catheter management is likely to be the only thing needed for social reintegration if it is performed as soon as possible by a skilled surgeon, and preferably within three months of developing the fistula. As this is likely to limit the length of time she is seen as abnormal by her family or community and thus perceived as an outcast. (C)
5. If possible, the choice should be available for women to recuperate in a designated space, within the repair facility or nearby, rather than going home and encountering the risk of behaviours that may make it likely that a recurrence of fistula occurs, due to an exacerbating physical event such as early sexual intercourse or heavy work. Also, peer counselling is more likely to be available in this space. (D)
6. Surgeons should consider social reintegration not just a social tool, but also as a means of ensuring that adequate follow-up of the postsurgical improvement in quality of life is done and reported on. At a minimum, there should be a review of individually defined success of surgery and the outcomes thereof, including continence and return to fertility and/or sexual life, as desired by the woman. (D)
7. Culturally appropriate pre- and postoperative counselling should be incorporated into services for repair of obstetric fistula to assess the woman's knowledge about her fistula condition and its cause, what to expect in terms of treatment and recovery, and how to care for herself following repair. As this has the potential to improve the physical and mental well-being of women and can help minimize behaviours that may make it likely that a recurrence of their fistula occurs. (D)
8. Appropriate counselling messages about the risk factors and causes associated with fistula should be targeted at family members (including husbands) and the community, as this can help to overcome the stigma, discrimination and misconceptions surrounding the condition and enhance her community inclusion, and be an opportunity for system change so that the woman does not present with another fistula in the future. (D)

9. Counselling should be seen as an opportunity for health providers to understand the socioeconomic, psychological and physical experiences that are faced by girls and women living with fistula, before and after surgery, so that they may give meaningful help. This will also help to generate knowledge on social reintegration processes and will help programmes consider a broader range of outcomes for women living with fistula. (D)

10. Consideration should be given to reintegration assistance such as education and life skills, and encouragement of private initiative through vocational skills development and microcredit support. As long as this is freely chosen it will not keep her unduly away from her community and will help her regain or improve her previous economic status and enhance her self-sufficiency and community inclusion. (D)

11. Vocational skills training should be given with the aim of providing women with alternative ways to generate income, without jeopardizing her recuperation, by teaching the woman a trade which is economically viable within her community.

12. Whenever possible, institutional reintegration services should be integrated into existing community activities or programmes directed to empowering women (e.g. education, skills training, and income generation). (D)

13. Reintegration programmes should consider developing criteria determining whom to support with socioeconomic interventions as funds may be limited and fistula consequences can vary dramatically by country and region. They should also be careful not to increase the burden of stigma and therefore inadvertently impede reintegration. Of particular concern should be women who are still incontinent, those who are deemed incurable, those who have no children and those whom have lived with fistula for a long period of time. (D)

14. Programs should consider the potential ethical dilemmas in reintegration such as providing targeted financial support or high-value goods to women with fistula in poor communities other than as part of a community approach. (D)

15. Community involvement can be scaled up by the use of motivational mobilizers in the form of women who are successfully reintegrated into their communities as this can contribute to community mobilization movements for safe motherhood, fistula case mapping, and referrals for treatment. Women should have a choice as to whether to be involved in such advocacy activities. (D)

16. Monitoring and evaluation should be an integral part of all reintegration programmes, to collect correlates of success and failure, and help understand sociocultural backgrounds, so that a context-specific approach can be used to design and deliver cost-effective, feasible reintegration programmes. (D)

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The Société Internationale d'Urologie

The Société Internationale d'Urologie is the world's only truly international professional organization serving the global urological community. Founded in Paris in 1907, the SIU now serves its members from its Central Office in Montreal, Canada.

SIU members represent the full spectrum of clinicians and investigators from all subspecialties that come together to diagnose, treat and support patients with urological disease.

The Society's mission is to enable urologists in all nations, through international cooperation in education and research, to apply the highest standards of urological care to their patients. The SIU is unique in its international scope and its commitment to effecting positive and sustainable change in nations across the world.

The SIU promotes its mission objectives through annual world congresses, training scholarships, equipment donation and maintenance in training centres, donation of teaching materials, and support of the International Consultation on Urological Diseases (ICUD).

Previous ICUD Consultations have addressed the following topics: Urogenital Trauma (2002), Bladder Cancer (2004), Congenital Genital Anomalies (2006), Stone Disease (2007), Penile Cancer (2008), Testicular Cancer (2009), Vesicovaginal Fistula (2010), Urethral Strictures (2010), Prostate Cancer (2011) and Male Lower Urinary Tract Symptoms (2012). Future Consultations include Congenital Anomalies in Children and Upper Tract Transitional Cell Carcinoma (both 2013).

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OBSTETRIC FISTULA IN THE DEVELOPING WORLD

It is globally accepted that for each maternal death, 20 women experience serious complications related to pregnancy. Obstetric fistula secondary to obstructed and prolonged labour is one of the most devastating maternal morbidities. Anecdotal reports suggest that about 80% of fistula patients live in sub-Saharan Africa. The holistic approach toward elimination of obstetric fistula includes prevention, repair of existing fistula cases, and social reintegration.

The first SIU-ICUD International Consultation on Vesicovaginal Fistula (VVF) was held in Marrakech, Morocco in 2010. This consultation gathered world experts to address key issues of VVF as regards epidemiology, prevention, treatment, complications, and social reintegration.

“Obstetric Fistula in the Developing World” presents the conclusions from this consultation. Produced by recognized fistula experts, this book offers comprehensive insights on the effect of VVF on women in the developing world, and provides a detailed report on its epidemiology, prevention, unmet needs, as well as its management. Through consensus recommendations by six committees of international experts, this book represents a milestone in the documentation of the evidence around the key issues of VVF. By comprehensively reviewing the scientific literature, and assessing its quality, the Consultation has laid the foundations for future clinical and research work, aimed at reversing the terrible tide of this condition.

The SIU, together with everyone involved in producing this book, hopes that readers will find this a valuable resource—an opportunity for fistula surgeons and fistula care providers worldwide to access evidence-based information on VVF that will benefit patients suffering from fistula.

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