Report of
Fistula Counseling Experts' Meeting
March 29 & 30, 2005
Kampala, Uganda

The ACQUIRE Project/EngenderHealth

USAID
FROM THE AMERICAN PEOPLE

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Equally importantly, EngenderHealth and the ACQUIRE Project are indebted to the past and present fistula clients, who agreed to be interviewed and serve as a sounding board to review the ideas expressed in this report. These women offered not only a window into their lives and the circumstances which led to their developing fistula, but also facilitated an understanding of the kinds of counseling from which fistula clients can most benefit. Their stories and their insights are the most critical indicator marking the need for counseling in general, the specific type of counseling needed, and the stage at which it can be most helpful as women who have experienced obstetric fistula begin to re-claim their lives and re-enter their communities.

Acronyms and Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ARV	Anti-retroviral
ANC	Antenatal Care
CBO	Community-based Organization
EmOC	Emergency Obstetric Care
FGD	Focus Group Discussion
FP	Family Planning
HIV	Human Immunodeficiency Virus
IEC	Information, Education and Counseling
RVF	Recto-vaginal Fistula
SRH	Sexual and Reproductive Health
STI	Sexually Transmitted Infection
USAID	U.S. Agency for International Development
VCT	Voluntary Counseling and Testing
VVF	Vesico-vaginal Fistula

Executive Summary

Background

Obstetric fistula is a devastating injury that occurs during childbirth, which can render a woman incontinent of urine and/or feces, and which has a number of severe physical, emotional and social consequences. While multiple efforts are underway to address the prevention and treatment of obstetric fistula, healthcare providers working in this area have repeatedly noted the dearth of comprehensive information and guidelines for counseling women with obstetric fistula.

Meeting Objectives

To address this specific need, EngenderHealth and the ACQUIRE Project brought together a group of 12 experts with experience in obstetric fistula counseling, in order to combine and refine the current knowledge in this area. Through interactive expert discussions, the objectives for this two-day meeting were to learn about the unique critical issues in counseling women with obstetric fistula, to understand when during the spectrum of care these counseling needs should be addressed, and to identify barriers to proper counseling and ways to overcome these barriers. Subsequent to the meeting, EngenderHealth staff conducted focus group discussions (FGDs) with current and former fistula clients to gain additional insight into counseling needs.

Findings

A number of participatory methodologies were used during the meeting to obtain valuable information and insights from the experts present. Detailed findings are outlined in the full meeting report. An overview of findings included:

Participants identified an array of myths and misperceptions surrounding the causes and consequences of obstetric fistula and its treatment, which are important to address during counseling. The profile of a typical obstetric fistula client was developed, followed by brainstorming of an extensive listing of the varied needs of women who suffer from this condition. These needs were arranged into the thematic groups of *Counseling* (comprised of Information/Education and Emotional Support), *Social Support, Management* (comprised of Material Support, Clinical Management and Socio-economic Support) and *Cross-cutting Issues*. Ideas for counseling clients with special needs, such as those who are considerably younger or older than average, those who are HIV-positive, those who are physically or mentally challenged, and those whose fistula is inoperable, were also elucidated. Participants outlined appropriate counseling messages for family members (including husbands), noting when during the spectrum of care family members should be involved. Meeting participants described appropriate behaviors for individuals who counsel women with obstetric fistula, as well as their concerns related to adequately addressing the needs of obstetric fistula clients. Participants brainstormed strategies to address these concerns, and shared no- or low-cost ways to improve the counseling environment in different types of settings, in order to address key issues such as privacy, confidentiality and staff shortages.

Recommendations

Recommendations from this meeting are presented in a framework devised by meeting participants (see full meeting report). This framework, in which a fistula client's experience in a facility has been divided into six sequential stages, includes key messages for fistula clients at each stage, and a list of providers and facility staff who should provide these messages. It also notes where partners and family members should be included in counseling (either with or separate from the client). The stages are:

1. FIRST CONTACT
2. CLINICAL (history taking, examination, diagnosis, discussion of treatment options)
3. ADMISSION TO WARD AND PRE-OPERATIVE MANAGEMENT
4. SURGERY
5. POST-OPERATIVE MANAGEMENT
6. DISCHARGE AND FOLLOW-UP

Although experts' meeting participants noted the importance of providing family planning (FP) counseling and information as part of a larger package of prevention and counseling needs, neither they nor FGD participants specifically emphasized the need to link fistula clients with FP services as a major focus of counseling. However, in planning for and implementing fistula counseling, it will be important for programs to raise awareness and demand for FP among clients as well as providers, in the form of FP training (knowledge, attitude and skills) and service support. This is reflected throughout the above-mentioned framework.

Key lessons learned during this meeting have been crafted in the form of "10 Tips to Improve Counseling Services for Fistula Clients," which are as follows:

1. Many women with fistula are illiterate and have not had the benefit of a formal education. For this reason, **drawing a diagram to help explain how the fistula was caused** may help her to understand her condition better than sharing informational materials or using medical terminology to try to explain the condition. In some situations, analogies may also be helpful.
2. Although many fistula clients have been shunned by family members or communities, it is also common for them to have isolated themselves. For this reason, **initial counseling must often include key messages of acceptance** to help women "find their voice" again. In the words of one participant, to learn "love getting and love giving" all over again.
3. In some settings, **providers themselves may hold attitudes or beliefs that further stigmatize fistula clients**. Counseling training should include a focus on addressing providers' own biases and potential misperceptions about women who present with obstetric fistula.
4. Women who are **former fistula clients are often excellent facility- or community-based counselors**. With a small amount of training, they can become valuable messengers.
5. **Sharing stories of women who have been successfully repaired may be an important strategy in pre-operative counseling** to allay fears and provide hope when women are at an especially vulnerable point in the treatment process.
6. In situations where fistula clients speak a language different from staff, **former fistula clients can also serve as effective translators**.

7. When possible, **involving family members and/or partners in counseling** is key to a client's overall success, as they can provide critical support for the client's emotional, material, and clinical needs both pre- and post-operatively. Family members and partners may be counseled together with the client or during a separate session, depending on the information being discussed.
8. As former fistula clients begin the process of reintegration, e**xisting community structures and support groups can be important to ease the process of re-entering society**.
9. One key **source of empowerment that counselors can relay is the woman's role in her own recovery process**. By noting the progress of their healing and taking charge of their own care, clients often begin to acquire a sense of control over their lives again.
10. In order to assist another health care provider to know about a fistula client's previous repair, **some facilities have created cards that include the surgeon's notes**. The card is given to the client when she leaves the facility and she is instructed to bring it with her if/when she seeks care again. This helps the client to control the flow of medical information, relay accurate details, and "own" the experience in a way that she might not otherwise.

Next Steps

The ideas that have been outlined in this report will be used to inform programming in USAID-supported obstetric fistula training and services, and will also be disseminated to individuals, agencies and facilities working on obstetric fistula. With support from the Bill and Melinda Gates Foundation, these findings will also be used to inform the development of a counseling training curriculum which will be tailored to the specific counseling and informational needs of women with obstetric fistula.

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Background

Obstetric fistula, a devastating injury that occurs during childbirth, has acute physical and mental consequences for a woman's health and wellbeing. A result of protracted, obstructed labor, obstetric fistula develops when prolonged pressure of the baby's head against the mother's pelvis interrupts blood supply to the tissues surrounding the pelvic organs, causing a hole to develop between the vagina and bladder to create a vesico-vaginal fistula (VVF) or between her vagina and rectum to produce a recto-vaginal fistula (RVF). Either condition can result in incontinence that leaves the woman leaking urine or feces or both. Women who endure obstetric fistula are usually a vulnerable population with particular needs that cannot be met by surgical repair alone. Often banished from their communities and rejected by their husbands or partners, many women lack information on the nature of their condition, the possibility of treatment, and the treatment process. Furthermore, they have limited access to general information on how to keep themselves healthy, including education and counseling on family planning, prevention of sexually transmitted infections (STIs) such as HIV, an understanding of the importance of postponing the next pregnancy, the need to plan for an assisted delivery, and the need to seek medical care if pregnant in the future in order to avoid complications. Years of shame, humiliation, and isolation may have eroded these women's self-esteem and sense of self-worth. In addition, they may require vocational training in order to generate an income to support themselves.

All of these issues can be addressed through targeted counseling and education, but many providers may need to develop new skills in order to best and most sensitively address the unique emotional, social, and health-related issues affecting women with fistula. Though a number of organizations, including EngenderHealth, are working to treat and prevent this condition through improved access to maternal health care and repair services, standards for high quality, comprehensive and appropriate counseling for women with fistula—necessary to safeguard health and weigh options—are lacking.

Introduction

During the process of conducting facility-based needs assessments on obstetric fistula services in twelve developing countries over the past two years, as well as during visits to sites where we are supporting fistula service provision, EngenderHealth has been asked repeatedly for technical assistance on how facility staff might counsel fistula clients. In some cases, staff members are trying to counsel as the situation demands, but feel overstretched and unsure of the most important messages. In other cases, staff members have a sense that they should be doing some kind of counseling, but simply do not know where to begin.

As a response to this call from the field, EngenderHealth has begun to plan for the creation of counseling guidelines for the spectrum of health care providers who work with fistula clients. As a first step, EngenderHealth and the ACQUIRE Project will use the ideas expressed in this meeting report, and validated by fistula clients interviewed, to inform programming in USAID-supported obstetric fistula training and services in Bangladesh, Uganda, and in other country and regional fistula programs supported by USAID. This report will also be disseminated to a wide variety of other individuals, agencies and facilities working on obstetric fistula, in order to share the collective expertise of counselors from various regions.

As a second step, with support from the Bill and Melinda Gates Foundation, a counseling training curriculum is being developed, tailored to the specific counseling and information needs of women with fistula.

To meet these two goals, in March 2005, EngenderHealth convened a meeting of obstetric fistula counseling experts in Kampala, Uganda.[1] This was the first time that professionals with experience in fistula counseling were brought together from different regions, with the specific aim of combining and refining the current knowledge on this issue. Participants included 12 experts on fistula counseling from Bangladesh, Eritrea, Ethiopia, Kenya, Nigeria, Sudan, Tanzania, and Uganda.

[1] While there are different types of fistula that undoubtedly call for different types of counseling, the focus of this meeting and the expertise of meeting participants was on obstetric fistula.

Meeting Objectives

The ***main objectives*** of the meeting were to:

1. Learn about critical issues for counseling fistula clients based on participants' professional experiences;
2. Consider how fistula clients' needs are similar to and different from other clients in obstetrics and gynecology wards;
3. Discuss at what point in the spectrum of care it is most appropriate to counsel fistula clients on key issues; and
4. Identify barriers to care and ways to overcome them when working with fistula clients.

Specific ***daily objectives*** over the course of the two-day meeting were as follows:

Day 1

1. To note common myths and misperceptions about obstetric fistula
2. To discuss provider concerns when working with fistula clients
3. To create a shared understanding of fistula clients' needs—emotional, physical, economic, etc.
4. To craft a shared sense of priorities of what is needed to meet clients' needs
5. To separate the fistula counseling priorities by sequential stages

Day 2

1. To review progress made in Day 1
2. To discuss key skills for providers who counsel
3. To identify which providers can and do serve as counselors at various stages of service delivery, and to brainstorm key messages that these providers should offer during sequential stages of service provision
4. To identify issues related to counseling fistula clients with special needs
5. To brainstorm no- or low-cost ways to make changes in facilities to improve the counseling environment
6. To create a list of key messages for partners, family members
7. To share next steps and wrap up

The agenda for both days is included in Appendix 2 of this report.

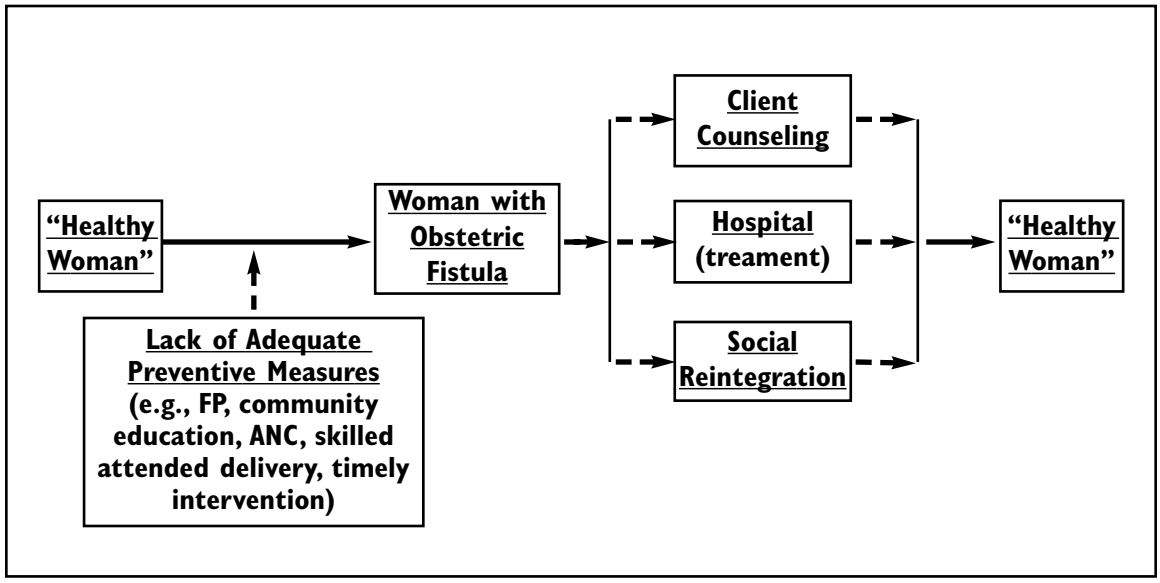
Methodology

The meeting methodologies employed over the course of the 2 days included a variety of participatory techniques that facilitated brainstorming on various issues related to counseling fistula clients. These techniques are outlined in more detail at the beginning of each of the following "Findings" sections.

Focus group methodologies were used to collect information from fistula clients on the day following the close of the experts' meeting. Participants included women varying in age from 18 to about 50, and ranged from women who were waiting to receive treatment, who had undergone several unsuccessful repairs, and those who had experienced successful repair. (Tools used to collect data can be found in Appendix 4.) A local translator provided simultaneous translation.

Steps in the Development and Treatment of Obstetric Fistula

Meeting participants developed the following framework for visualizing the trajectory of a healthy woman who, due to lack of adequate preventive measures, develops obstetric fistula, and is ultimately restored to health through essential interventions. Though this meeting was intended to focus on facility-based counseling for fistula clients (and other key supporters), meeting participants also noted the critical role of prevention, as well as social reintegration and community education activities in addressing a fistula client's needs at different points in time, as well as in preventing future fistula.



Myths and Misperceptions About Obstetric Fistula

In many countries where obstetric fistula is prevalent, cultural beliefs and practices shape a client's ability and desire to seek medical services. While some community members may correctly recognize unrelieved obstructed labor as the cause of obstetric fistula, others may attribute the development of fistula to a variety of other causes, many of which are believed to be linked to the woman's personal and/or social characteristics or behaviors. Targeted counseling can play a key role in dispelling any myths or misperceptions that clients and their families have about why fistula occurs and how it can be treated and prevented. In this session, meeting participants relayed causes of fistula that they have heard of in their countries.

A woman (or others in her community) may believe that she has developed a fistula because:

1. She had an affair with a man who is not her husband.
2. She received a curse from God. She may believe that during labor, people prayed for her, but God did not hear/reply to their prayers.
3. She was catheterized because she was drinking too much water during her prolonged labor and the catheterization resulted in a fistula.
4. Those who were jealous of her (perhaps due to her economic status or because she had many children) performed witchcraft against her.
5. Her stepmother performed witchcraft against her.
6. A traditional birth attendant pinched her bladder during labor.
7. The providers at a health facility pinched her bladder with fingers or instruments used ostensibly to help her deliver the baby.
8. She had a sexually transmitted infection.
9. She or her mother (while pregnant) had offended the spirits of the river. Annoyed, the spirits created a river within the woman, and she will not stop leaking until she appeases the spirits.
10. She was a young girl married to an older man.
11. She was cursed by her parents for getting pregnant before marriage.
12. She failed to pay her dowry and was punished as a result.
13. She had tried to abort her baby while she was pregnant.

Meeting participants also noted other cultural beliefs and practices that contribute to the incidence and prevalence of obstetric fistula:

1. Based on her religion, a woman may feel that she must accept her fistula as her destiny, and she should live with this for the rest of her life. She believes that as a result of her suffering, she will be rewarded—therefore she should not seek treatment.
2. Some societies expect a woman to have a natural birth, and if she can't, she is a coward or she is "not woman enough". In other societies a woman is expected to deliver her first-born child at home. Such practices may prevent a woman from going to a facility.

The diverse array of beliefs surrounding obstetric fistula presented here is likely just a sampling of the prevailing beliefs among communities where women suffer from fistula. These beliefs clearly point toward the need for dispelling myths and misperceptions and raising awareness about obstetric fistula through counseling and other activities.

Profile of a "Typical" Obstetric Fistula Client

The objective of this session was to build a profile of a typical fistula client, with the aim of helping program managers and providers to better understand and care for women with fistula. Participants identified some similarities among fistula clients in the communities where they work, while acknowledging that each woman's situation is ultimately unique.

> **"[A woman with] fistula is treated like she has a contagious disease."**
> —Rahmat Hassan Mohammed, FORWARD/Nigeria

The standard client generally ranges from an adolescent (14-19 years) to a much older adult. Older clients are generally women who have lived for several (or many) years with fistula. In general, women with fistula are very poor; they lack means to use transport and to get to a facility in time to receive emergency obstetric care. The vast majority have not had the benefit of formal education, evidenced by the low level of literacy noted among them. Their nutritional status is generally low, and most are from remote, rural areas.

Fistula clients tend to have a low self image and often believe that fistula is a condition unique to them. Many are ashamed, downcast, and avoid eye contact when speaking with others. In some cases, the woman has been abandoned by her partner, who may have left to remarry. In such situations, a woman is typically unable to support herself and will move in with her parents or another family member. In some instances, family members take the woman in graciously. In others, she is treated like a prisoner, or, as one participant noted, "forced to sleep in a cowshed." Women may also isolate themselves out of fear and shame of smelling bad, abandoning their homes before their partners have the chance to leave them. In other cases still, the couple remains together, often for the sake of their children. In all of the above scenarios, fistula affects not only the woman but those who care for her as well.

Some women also experience rejection from their broader communities, which imposes isolation upon them. Meeting participants noted that in some instances women with fistula are barred from attending church. Additionally, those who had a business before developing fistula often become social outcasts afterwards; community members refuse to purchase goods from them (especially when cooked food is involved), ruining their businesses and decreasing their ability to support themselves. Some are also forced into commercial sex work or other forms of unskilled labor to earn a living.

"Every Woman with Obstetric Fistula Needs…"

Given the variety of situations a "typical" fistula client might face, women who experience obstetric fistula have a variety of needs, ranging from medical and clinical, to emotional and social. During this session, participants brainstormed the various needs of fistula clients. Participants were each given five cards (or more if desired) on which they were asked to record, based on their experiences, what they felt the needs of a fistula client are. Participants wrote down one need per card, and then had the opportunity to explain each of their choices to the larger group and post them on the wall. The cards were subsequently used in a card-sorting exercise, whereby participants organized the various needs identified according to thematic categories. Participants developed categories at the same time the needs were being sorted on the wall, with frequent alterations made to reflect the course of the discussion.

Participants organized the needs of women with obstetric fistula into four broad categories: **Counseling** (including Information/Education and Emotional Support needs); **Social Support**; **Management** (including Material Support, Clinical Management, and Socio-Economic Support needs); and **Cross-cutting Issues**. Below is a list of the needs identified, grouped by category. Each need listed completes the sentence "Every woman with obstetric fistula needs…"

card sorting exercise

"We must teach women to read and count because when they are rehabilitated and begin to make money, they must know how to count it!"
—Rahmat Hassan Mohammed,
FORWARD/Nigeria

I. COUNSELING

A. Information/Education:

1. To understand what caused her condition (to dispel any myths/misperceptions, and so she can cooperate during management)
2. Education about her type of fistula and possible operation
3. Information on the scope of treatment and future hope
4. To understand the outcome after treatment
5. To understand her own role in managing her condition
6. Information on issues around reproductive health and sexual rights (including FP)
7. Clear post-operative instructions
8. To know about the availability of fistula repair
9. To know that she can still have children and lead a normal life
10. Counseling in her own language
11. Providers with up-to-date information
12. Information on the need for her next delivery to be in a facility
13. Education on good nutrition
14. Knowledge on the importance of her own personal hygiene
15. A discussion about fistula, with the help of a diagram
16. Information on operative and post-operative complications
17. To be given simple, clear messages
18. To learn how to cook her own food
19. To know the degree and extent of the injury she has, since it will impact the outcome of her surgery
20. To be empowered
21. Information on options for clients with unsuccessful outcomes
22. To be involved in using her own knowledge and experience in bringing other fistula clients to facilities

I. COUNSELING (continued)

B. Emotional Support (counselor-provided):

1. A warm welcome at the facility
2. An understanding of "love-getting" and "love-giving"; to understand the true meaning of love and care
3. A discussion around the details of care
4. Information on fistula success stories
5. To have her fears dispelled
6. Sympathy/empathy and love
7. Support before and after successful repair
8. To understand that she is not the only one with this condition
9. To get to know staff and other clients at the facility, to feel more comfortable
10. To have her privacy and confidentiality maintained
11. Coping skills to manage depression
12. To have access to friendly services

II. SOCIAL SUPPORT

Social Support Provided by Family/Community:

1. To be in a good environment
2. Social consultancy (needs to feel loved, to be talked to)
3. Reintegration into her family and community (using existing community support structures)
4. To share the problem with friends
5. Dignity
6. Community support structures that reach fistula clients
7. Support from and understanding of her condition by family, friends, community
8. To stay with her parents, who understand her problems and will care for her
9. People who are understanding (providers and relatives)
10. Financial support for transport
11. A support group to share experiences

III. MANAGEMENT

A. Material Support:

1. Nutritious food; knowledge of preparing balanced meals
2. A bar of soap, cosmetics
3. Clean clothes, shoes
4. Sanitary pads or clean cloths to contain incontinence
5. Material support for her and her children
6. Clean water to drink
7. To be in a good environment
8. Her own bed (i.e., not shared with other clients)

III. MANAGEMENT (continued)

B. Clinical Management:

1. Successful repair with no delays 2. Good nursing care 3. Access to quality fistula repair services 4. Access to quality emergency obstetric care services (before and after successful repair) 5. Access to other sexual and reproductive health services after repair 6. Appropriate treatment	7. Respect 8. Pre-operative physiotherapy (if necessary) 9. Adequate diet (if necessary, in preparation for surgery) 10. Well-trained and competent health providers 11. Easy access to services

C. Socio-economic Support:

1. Free or affordable services and treatment 2. Education (literacy/numeracy)	3. Income-generating skills development 4. To be self-sufficient (and care for her children)

IV. CROSS-CUTTING ISSUES

Cross-cutting Needs:

1. Follow-up after repair 2. Good nutrition 3. To be in a good environment	4. To lead a normal life and have children if she so wishes 5. Easy access to services within health systems

Counseling Clients with Special Needs

Once participants had the opportunity to brainstorm the overall educational/informational, support and management needs of clients who have obstetric fistula, a second session focused on the counseling needs of clients whose circumstances force them to deal with additional concerns, not necessarily related to fistula. Though neither all types of clients with special needs nor all of their needs could be addressed in the limited time available, participants identified the following sample target groups and corresponding needs:

Younger women

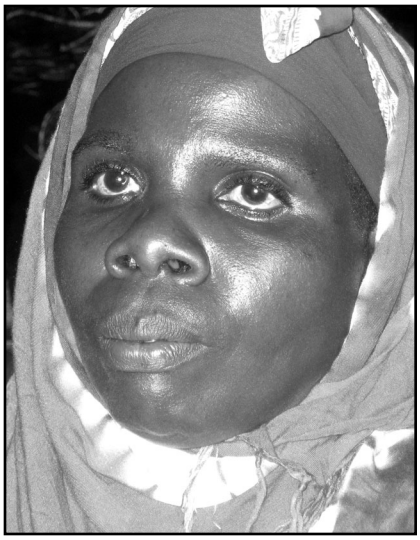
Younger clients tend to be less mature and may have tendencies toward shyness; they may not feel free to express themselves as openly as older women would. In cases such as these it is important for a counselor to make an extra effort to build rapport by using simpler language than might be appropriate for an older client. Younger women may also experience more unwanted pregnancies than older women because of forced early marriage. The emotional trauma sometimes associated with that event, coupled with the struggle of dealing with fistula, sometimes combines to make a young client especially uncommunicative.

Her desire may also be not to delay pregnancy, making her reproductive health counseling needs different from those of an older woman.

Younger women who are unmarried may face community rejection for having gotten pregnant at an age considered too early. They may have been suspended from school as a result, increasing their shame and amplifying the dread of discussing their situation with anyone.

Older women

In contrast to some younger women, older clients may already have other children. Therefore, they may not desire additional children, and may focus less on their future reproductive capacity. Older women may have lived for several years with fistula and perhaps undergone numerous attempts at repair, which can cause severe scarring and render further successful surgery difficult. In addition, their increased age may decrease the ability of tissue to heal.



fistula client

Older women may also need health education and counseling focused more on menopause and the issues surrounding it. The need for referrals to other reproductive health services, such as cancer screening, may be pertinent among this group as well.

Meeting participants thought that at a community level, reintegration may or may not be easier for this group than for younger women. On the one hand, in many settings where fistula is a problem, age earns a woman increased respect, which would remove many barriers to social reintegration. On the other hand, it was noted that older age also brings more visibility within a woman's family and/or community; the embarrassment she might feel could become pronounced as a result, making issues of social reintegration more complex.

HIV+ women

Participants noted that women who are HIV positive or who have full blown AIDS are less likely to experience full healing, and would therefore require supporting messages (in the form of nutrition education, for instance) to help promote maintenance of health.

Referrals are essential for women with HIV on several levels. First, even if her fistula is successfully repaired, in addition to general messages about managing her repair and seeking a Cesarean section in the case of future pregnancies, she must be advised on the possibilities of mother to child transmission of HIV and related issues should she become pregnant again. Second, as anti-retroviral (ARV) medications become increasingly available, HIV positive women should be linked to these services, as well as to HIV support and treatment organizations if they exist. Third, with some clients, HIV may be easily identifiable due to the existence of opportunistic infections. Counselors and providers should use this as an entry point to engage the client in discussions about options, making her aware of the range of services available to address such problems.

Women who are physically disabled

Counseling a client with physical disabilities will likely involve more family participation than for clients without such challenges, particularly if the disability is such that the client is not able to care for herself. She may also have special communication needs, making it necessary for a counselor to have skills related to her disability (sign-language, for instance, for someone who is deaf).

Women who are mentally or developmentally challenged

Participants suggested that a client with mental or developmental challenges might need to be repaired under general anesthesia (rather than local) because of the complexity of the clinical management issues. A circumstance like this would also influence staffing of the surgical team.

In some cases, a woman may present with severe and unmanageable depression, for which she may require psychotherapy, medications, etc. This may also have caused her to stop eating for a period of time before coming to the facility. In such cases, a woman would require a host of physical rehabilitation interventions prior to surgery.

Finally, women with mental illness, developmental challenges, and those living in distressed situations pose special concerns regarding the voluntary nature of their decisions – especially if permanent contraception is being considered. Women with severe mental or developmental challenges may require extensive counseling around limitation of future fertility (e.g., long term contraception) because they may be incapable of understanding specific messages related to short term abstinence and self-care during the recovery phase, and may also be an easy target for abuse. If the client is legally able to give informed consent, she must be carefully counseled, in terms that she understands. Family participation in counseling might also be necessary, if the client is unable to understand key messages.

Women with inoperable fistula

Participants had several suggestions for the management of clients with a fistula that is determined to be inoperable. In terms of *clinical* management, ideally, clients should be counseled on options for urinary diversion (such as ileal conduit) or vaginal reconstruction (when the vagina is nearly closed from a surplus of fibrous tissue). Counselors should also share key messages with partners and/or family members, whose lives would undoubtedly be affected by caring for a woman who will live with fistula for the rest of her life. The family must be sensitized to the importance of their critical involvement in emotional and physical support and care. Finally, issues related to the maintenance of a sexual relationship when a fistula cannot be repaired would require counseling both for the client and her partner (specific issues will vary among clients).

An "Ideal" Counselor

During this session, participants read a case study of a woman who had developed an obstetric fistula (see Appendix 3). Subsequently, to demonstrate an example of poor counseling, two participants role-played, one playing the part of a counselor and the other playing the fistula client (as portrayed in the case study). Participants then discussed how the counseling session

"Good counseling helps a fistula client become herself again."
—Feddis Mumba, AMKENI PROJECT

could have better met the client's needs. Two different meeting participants then acted out a good counseling session, in which the counselor better addressed the needs of the client. Meeting participants discussed this demonstration as well.

During the discussion following the "bad counseling" role-play, participants noted a number of factors that led to a **poor counseling session**, including:

- Lack of privacy for the client (the counselor exchanged words with colleagues during the course of the session)
- Little physical interaction or eye contact between the counselor and client
- Counselor held her nose due to the client's odor, and asked the client to sit on paper so as not to soil the chair
- Counselor did not take the time to establish rapport with the client, and immediately began by asking how and why the woman developed a fistula
- Counselor checked the time frequently, was abrupt, asked close-ended questions, and did not give the client a chance to speak or ask questions
- Counselor's attitude was extremely judgmental; she blamed the client for having developed a fistula
- Counselor did not speak in simple language that the client could understand, and did not explain to the client what she was doing when taking her blood pressure
- At the end of the session, the counselor told the client that they would 'fix her', but gave no explanation of the process or possible outcomes

Participants agreed that the counseling session was hostile and left the client disappointed, and that after such a session, the client would have left feeling further stigmatized, with no expectation that the facility would be of help to her.

After a role-play of an **improved counseling** session, participants noted positive and appropriate behaviors. The counselor smiled, welcomed the client warmly, sat close to her, and offered her something to drink. She assured the client that she was not alone, and that there were many other women who suffer from fistula. She also had good listening skills, asked open-ended questions, spoke in simple language, and listened carefully to what the client said. By behaving in such a manner, participants felt that the counselor helped the client to feel comfortable, which would allow her to "open up." The client might also "spread the word" about the counselor, which would encourage more women to seek fistula services.

counseling role play

During this discussion, meeting participants raised the issue of balancing empathy and professionalism. While empathy is important, the counselor must also make sure that he/she is giving the client all of the necessary information. From this discussion, participants agreed that the time needed to make a client feel comfortable enough to discuss her situation will depend on the client's personality, age, particular condition, and/or culture, and that for many, it can take a longer period of time than available during a short role play exercise to begin to feel comfortable discussing her situation with a provider.

In terms of who will provide counseling to fistula clients, participants noted that this would be determined in large part by the availability of staff in a given facility. For instance, in facilities experiencing staff shortages, full-time counselors may not be available, and doctors and nurses may not have the time available to conduct in-depth counseling sessions with clients. Participants suggested that one way to address this would be to train outreach/community health workers (some of whom might be previous fistula clients) in counseling skills. For a full list of individuals identified as possible counselors and messengers, see table entitled "Counseling for Fistula Clients: Key Counseling Needs and Messages for Clients at Various Stages of Service Delivery" in the Recommendations section.

"Family members should receive counseling too, so they know that even if a woman's repair is not successful, she should be treated like a human being."
—Fistula Client, Kitovu Mission Hospital

Key Messages for Family Members

This session included a group discussion on how most appropriately to involve family members in counseling and support of fistula clients. Participants noted that *who* is involved, and at which stage in a client's care, will depend on a client's particular situation. For instance, often a family member arrives with the client when she seeks fistula repair services and functions as an attendant. In other cases, the client may arrive alone, but when repaired, returns to some form of extended family. In either situation, family members can play an important role in caring for a client and relaying important information before, during and/or after surgery.

Meeting participants considered **partners/husbands** to be especially important in the overall success of repair, noting particularly the potential of the fistula to recur if a woman fails to abstain from sex for a number of months after repair and discharge. In order for men to be aware of what is expected of them after treatment, they need to be counseled as well. **Parents, children, siblings, and in-laws** were identified as key family members who could benefit from direct counseling, depending on the situation of the fistula client. In addition, **friends** were considered to play important roles in delivering key messages in some cases, as well as **community leaders**, who in some communities can help to ensure a woman's access to health care services. **Employers and teachers** may also play a role in a woman's recovery, particularly in situations where girls or women might have the opportunity to return to previous employment or school.

Meeting participants agreed that there are situations when a support person should be included in the same counseling session as the client, for instance, in order to dispel any myths about why the client had gotten a fistula in the first place, cover issues related to post-operative care, and understand the need to support her re-integration back into the community. Interestingly, children may play an important role in this process, especially if they are able to help with household chores such as washing and fetching water or wood while the client recovers. When the client is young herself, a second set of ears can be important in a counseling session in order to make sure that the information is understood by the client.

"The overall success [of repair] depends on the involvement of men."
—Henry Kakande, Masaka District Hospital

In other situations, such as when issues of sexuality are being discussed, participants noted that it is most important to counsel a client individually and, with her permission, include her partner or husband, if he is still

part of her life. They suggested that a partner might play a key role in helping to decrease her potential for depression by supporting her emotional and physical needs, and assisting with material support. He must also be counseled on and agree to a period of abstinence from sexual relations following the surgery. Given appropriate counseling and information, partners (or other decision makers) can also play an important role in preventing recurrence of fistula by ensuring that a woman seeks medical care during future pregnancies.

Finally, regarding issues of how best to support the client emotionally and help her to regain a sense of self, participants suggested that her family members or attendant(s) may need to be counseled separately. In these counseling sessions, providers can more openly discuss how family members or friends can help the client improve her self-esteem.

Provider Concerns

This session provided an opportunity for participants to discuss the specific concerns they have when working with women with fistula. A "wheel exercise" methodology was used during this session, whereby participants made 2 circles; 6 people stood in a small circle with their backs to each other facing out, the other 6 stood in a slightly bigger circle facing the smaller circle. The facilitator asked a series of questions regarding provider concerns to those in one circle, and gave each participant a minute to respond to the question by directing his/her comments to the person he/she was facing. The groups engaged in a short dialogue, and then reported their responses back to the larger group. After all answers to the first question were shared, the outer wheel moved one person in a clockwise direction, and the exercise was repeated for a different question; this time, the question being directed to the people in the outer circle. This methodology allowed for participants to interact one-on-one with different meeting participants, while also enabling the entire group to hear and react to each small group's discussions.

Through this exercise, participants recognized the dearth of providers in most facilities, noting that those who conduct counseling will be adding this as another responsibility to an already heavy workload. Given this reality, emphasis was placed on the need to develop strategies on how best to counsel clients without having a negative impact on other equally important services. Though challenges to providing services depend greatly on staffing patterns, client load, and other external factors, among the participants' general **concerns when treating fistula clients** were to:

- Help a woman to address any physical problems developed while in transport to facility
- Help a client overcome low self-esteem and reestablish a sense of self
- Ensure that the client is treated and repaired successfully
- Provide appropriate, useful and comprehensive counseling

Contributing to provider concerns about their ability to provide the above services are the lack of adequate facilities to provide quality care (including space, equipment, beds, expendables and consumables), the need for additional clinical training for doctors and nurses (including training in use of appropriate equipment), the need to hire counselors, and the issue, as one participant mentioned, of visiting surgeons "owning" the equipment that they use when conducting repairs at the local facility.

Participants also noted some of their concerns specific to treating clients who present with **complicated fistula cases**, including:

- Providers' inability to recognize complicated cases in a timely manner
- The long period a woman might have to wait before receiving services, particularly if a visiting provider is responsible for all or most of the repairs conducted
- The need for mobilizing outside resources to supply a facility with necessary equipment and supplies to address complicated cases
- Lack of knowledge among providers to simultaneously address other issues that a woman may present with, such as HIV/AIDS

Participants were also asked to describe the **attitudes among providers toward fistula clients** in their facilities, for which responses varied. At some facilities, participants noted that providers are rude to clients, but that blaming of clients frequently stems from providers' frustration with the backlog of cases, equipment and staff shortages, and/or a woman's inability to pay for the services she requires. In some settings—particularly in those where stand-alone fistula services do not exist—providers might also be anxious because they do not have adequate time and space to care for women. Providers also sometimes stigmatize fistula clients, preferring to work in other wards because women with fistula are considered "unclean" or "impure." In some settings, however, participants noted that providers are highly motivated and caring towards fistula clients; this was noted especially in settings where the providers are repaired fistula clients themselves (e.g., as nurses, counselors, health educators).

Participants identified some **strategies to address these concerns**, including:

- Informing clients to follow instructions, before, during and after surgery (regardless of outcome of surgery)
- Involving client's family and community members in counseling—particularly in terms of assisting with follow-up—since a fistula client's medical, as well as psychosocial, needs will extend over time (especially with complicated cases that may require long waiting time before surgery)
- At facilities where complicated cases cannot be addressed by facility staff themselves, counseling the client and referring her to a facility where complicated cases can be repaired
- Providing the client with information about specific interventions to address her condition, such as pelvic floor exercise for stress incontinence
- Minimizing in-patient post-operative time so as to improve shortage of post-operative beds
- Encouraging clients to maintain self-esteem (particularly if attempted repair was unsuccessful), and providing counseling so she can cope with her situation until and when she returns home
- Mobilizing community leaders to help raise funds for equipment or other facility needs

No-/Low-Cost Ways to Improve the Counseling Environment

The goal of this final session was to gain information on strategies to improve the counseling environment. It also provided an opportunity for meeting participants to share

concrete, practical solutions to problems that many of them face on a daily basis when providing fistula services. Meeting participants read a case study of a health facility in which a variety of barriers to counseling exist (see Appendix 3), and then were asked to identify these barriers and related solutions, as well as to describe any additional barriers that they may have encountered in providing fistula counseling services. The "wheel exercise" methodology, as described in the section 'Provider Concerns' above, was also used in this session.

One of the major challenges identified by participants was the l**ack of space for counseling**, and, as a result, **lack of privacy**. Suggested solutions included:

- Conduct counseling under a tree outside
- Provide visual privacy (for example, with a curtain)
- If funds exist, compartmentalize the existing counseling space (e.g., build a wall)
- Find another space in the facility that may be available periodically
- Share an existing space that is used for other counseling sessions, alternating hours with the other service so that privacy is assured

It was noted that if a **client appears to be uncomfortable** during a counseling session, the counselor should find out why she is feeling so, and should do whatever is possible to make her feel comfortable, as this will facilitate trust and communication.

Shortages of staff can lead to little or no time available to conduct counseling. To address the challenge of **staff shortage**, one participant suggested that staff in a facility be redeployed. Additionally, women who have undergone numerous unsuccessful repairs or who have fistulas that are too complex to be repaired can be **trained as volunteer nurse aides** (or other aides) **and equipped with counseling skills**. Not only is this a low-cost method for increasing staff coverage, but it is also a way to empower a woman, helping to give her life more meaning.

Communication can sometimes be difficult when **language barriers** exist. A possible solution to this could be to look among other clients for an interpreter.

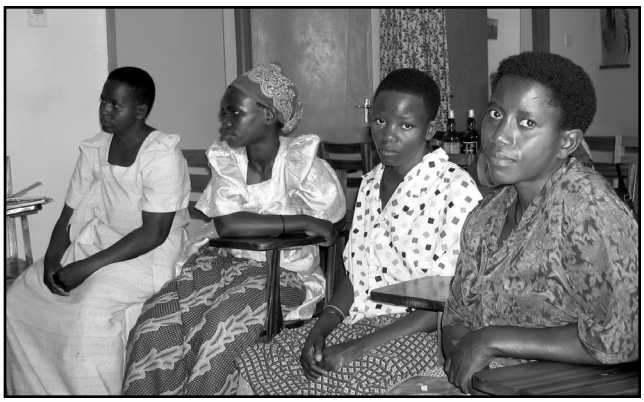
Maintaining clients' confidentiality is another important issue facing many facilities. Participants suggested this issue could be addressed both through proper training and by improving counseling spaces.

A number of meeting participants mentioned that the **lack of proper family planning services and limited information, education and counseling (IEC) materials** were problems faced in their facilities. Potential solutions for obtaining IEC materials included coordinating with other facilities and government institutions who may have these materials, or drawing/writing necessary information on a wall chart.

Providing skilled counseling is a constant challenge in many facilities, and participants suggested that **facilitative supervision**, in addition to proper training, may be of use.

Voices of Fistula Clients

On the day following the counseling experts' meeting, EngenderHealth staff held focus group discussions (FGDs) with 29 women at Kitovu Mission Hospital in Masaka District. Participants included women who were waiting for repair for the first time, women who had been successfully repaired, and those who had undergone one or more unsuccessful repairs. The purpose of conducting the FGDs was to seek the input of current and former fistula clients on the priority issues brainstormed by the experts, as well as to gain any additional insight on the counseling needs of fistula clients prior to, during, and after surgery.



focus group discussion

In general, FGD participants confirmed the needs and issues that the counseling experts outlined during the meeting. The most common needs expressed by FGD participants were for reassurance, hope and encouragement from providers, particularly if they had not received this type of support from their families. Women also confirmed that they were anxious to hear "success stories" of successfully repaired clients, either from providers or from treated clients themselves.

Participants expressed a number of informational and educational questions and concerns, all of which can be addressed during targeted counseling sessions. These include information on how they got their fistula/how fistula is caused, what the provider will be doing during the course of treatment, why menstruation had ceased (if it had), why some women have multiple fistulas, what happens during surgery, whether it is possible to undergo successful repair after numerous failed attempts, and how long a women has to wait to resume physical work after surgery.

Participants also noted that they want providers to involve family members, and particularly their partners, in counseling. A number of participants emphasized that if a husband accompanies the client to the facility, he should leave with information regarding how long to abstain from sex after the surgery. Participants also wanted providers to inform clients' husbands to "handle them with care" (physically and emotionally), both before and after surgical repair. One participant stressed the importance of counseling family members, so they know that "even if a woman's repair is not successful, she should be treated like a human being."

The majority of FGD participants indicated that the information they had received about fistula they had obtained through other women who had been to a facility for fistula repair before, reinforcing both the important role of previous fistula clients as peer educators, as well as the need for improved counseling services and training for providers at facilities that offer fistula services.

Recommendations

Based on information gathered during the various meeting sessions (and validated by the FGDs), meeting participants devised the following framework, outlining which types of providers and facility staff can and/or should serve as counselors during the various sequential stages of service delivery, and which needs—including informational/educational, emotional, social, and clinical—these individuals should address through counseling. Participants also noted those stages where family members and partners should be involved in counseling (either in a session with the client or separately).

Participants emphasized that all staff at a service delivery site—from the clinicians to the gardeners and gatekeepers—need to be informed of the availability of fistula repair services at the site, and to be sensitized to the specific needs of fistula clients, since all staff play a role in facilitating service provision and delivering key messages at various points in a client's stay. The term "counselor" is therefore defined somewhat loosely in this framework, reflecting the array of staff that a fistula client might interact with on her visit to a health care facility.

Although experts' meeting participants noted the importance of providing FP counseling and information as part of a larger package of prevention and counseling needs, neither they nor FGD participants specifically emphasized the need to link fistula clients with FP services as a major focus of counseling. However, in planning for and implementing fistula counseling, it will be important for programs to raise awareness and demand for FP among clients as well as providers, in the form of FP training (knowledge, attitude and skills) and service support. This is reflected throughout the 'Counseling Needs/Key Messages' section of the following framework.

Though this framework is intended to be adaptable to a variety of healthcare settings, participants acknowledged that factors such as staffing pattern, client load, and available space and time will greatly affect how service delivery and counseling provision play out in actual healthcare settings. This framework was developed with the idea that, in the event that services are integrated and time is limited, a clearly defined minimum package of clients' needs (and key messages required to address these needs) should be developed as a general guideline, which will invariably be modified based on a setting's particular circumstances.

Counseling for Fistula Clients: Key Counseling Needs and Messages for Clients at Various Stages of Service Delivery

Stage	Responsible Staff/ Counselor(s)	Counseling Needs/ Key Messages
STAGE ONE: First Contact ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼	• Gatekeeper/security person • Receptionist/clinical writer • Nurse/midwife • Clinical officer/assistant	• Warm welcome • Directions to appropriate unit • Empathy/respect • Understanding of client's condition (physical, emotional, etc.) • Confidentiality (when possible) Note: Needs and counseling messages will vary depending upon whether the client has already been diagnosed with fistula upon arrival or whether she is presenting for the first time.
STAGE TWO: Clinical (history taking, examination, diagnosis, discussion of treatment options) ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼	• Clinician (e.g., duty doctor, nurse, midwife, clinical officer, medical officer)	• Assurance of privacy and dignity • Sharing of success stories (e.g., past clients could be there to talk with clients, or facility could show video/pictures of cured fistula clients with children) • Help to form client social support groups within facility • If condition not treatable, give information on community support networks, and discuss how she will go about her life *Information on:* • Present condition and its causes (including dispelling of any myths/misconceptions about fistula) • Possibility of treatment and/or treatment options (e.g., if client told she has to wait for surgery, she should understand why) • Personal hygiene • Good nutrition • Length and outcome of treatment Note: Partners and/or family members should be involved in counseling from this stage on (either with client, or separately).

(continued)

Counseling for Fistula Clients: Key Counseling Needs and Messages for Clients at Various Stages of Service Delivery (continued)

Stage	Responsible Staff/ Counselor(s)	Counseling Needs/ Key Messages
STAGE THREE: Admission to Ward and Pre-operative Management ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼	• Nursing staff (e.g., public health nurse) • Doctor • Clinician • Social worker • Counselor • Previous fistula client (e.g., as peer counselor, community health educator) • Facility support staff	• Warm welcome • Description of procedure (including dangers, possible complications) • Alleviation of fears regarding surgery • Introduction of fistula client to other clients in the ward • Sharing of success stories • Discussion of client's role in own management of condition *Information on:* • Personal hygiene • Good nutrition • Bowel care • Pre-operative clinical management
STAGE FOUR: Surgery ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼ ▼	• Theatre staff/nurse • Anesthesiologist • Urologist/surgeon • Facility support staff	• Reassurance/comfort/hope • Alleviation of fears regarding surgery • Information on type of anesthesia to be used, risks of anesthesia, pain • Reiteration of steps of procedure • Respect and dignity Note: Counseling needs during intra-operative period may vary depending on whether the surgery is conducted under general or spinal anesthesia.

(continued)

Counseling for Fistula Clients: Key Counseling Needs and Messages for Clients at Various Stages of Service Delivery (continued)

Stage	Responsible Staff/ Counselor(s)	Counseling Needs/ Key Messages
STAGE FIVE: Post-operative Management (min. 14 days post-op) ▼▼▼▼▼▼▼▼▼▼▼▼▼▼▼▼▼▼▼▼▼▼▼▼	• Nursing staff (e.g., public health nurse) • Doctor • Clinician • Social worker • Counselor • Previous fistula client (e.g., as peer counselor, community health educator) • Facility support staff	• "Welcome back!" • Clear post-op instructions in simple language (e.g., for catheter care) • Reassurance; addressing of client's feelings • Understanding of any complications/ danger signs *Information on:* • Outcome of surgery • Position and mobility • Good nutrition • Pain relief • Physiotherapy (if necessary) • Necessary period of abstinence from sex (if repair successful) • Need for antenatal care and hospital delivery (likely by C-section) for future pregnancies • Availability of SRH services and rights (including FP) Note: Partners and/or family members should receive counseling at this stage, to provide a complete understanding of what will be required of them to assist in post-op management. Depending on specific health facility norms, family may also be involved immediately post-op to help bring food and to cook, to find water for cleaning, etc.

(continued)

Counseling for Fistula Clients: Key Counseling Needs and Messages for Clients at Various Stages of Service Delivery (continued)

Stage	Responsible Staff/ Counselor(s)	Counseling Needs/ Key Messages
STAGE SIX: Discharge and Follow-up	• Nurse • Clinician • Counselor • Social worker • Community health worker • Partner/family members (if they have already received counseling themselves)	*If surgery successful:* • "Congratulations!" • Re-iteration of information on necessary period of abstinence from sex • Messages on delaying pregnancy/FP/contraceptive choices (if desired) • Information on continued personal hygiene and good nutrition • Reiteration of need for antenatal care and hospital delivery (by C-section) for future pregnancies to prevent fistula • Linkages to support groups, where available (may be through CBOs) • Discussion of income generating activities and educational opportunities, if possible and/or available • Information on complications and danger signs, and need to return for follow-up • Information on stress incontinence • Information on HIV/AIDS and other STIs • Referrals for other SRH services *If surgery unsuccessful:* • Hope for future success • Discussion of income generating activities and educational opportunities, if possible and/or available • Linkages to support groups, where available (may be through CBOs) • Referrals for other SRH services *Information on:* • Why surgery was unsuccessful • Future surgery (whether possible or impossible, and if possible, when and where) • Personal hygiene and good nutrition • Managing incontinence (e.g., special exercises) • Messages on delaying pregnancy/FP/contraceptive choices (if desired) (especially if/as she waits for next operation) • HIV/AIDS and other STIs • Possible complications and/or infection • Stress incontinence • Catheter care (if catheter needed)

From the meeting sessions and focus group discussions, a few salient "counseling tips" emerged, which may be useful for programs that currently provide (or intend to initiate) counseling services for fistula clients:

10 Tips to Improve Counseling Services for Fistula Clients

1. Many women with fistula are illiterate and have not had the benefit of a formal education. For this reason, **drawing a diagram to help explain how the fistula was caused** may help her to understand her condition better than sharing informational materials or using medical terminology to try to explain the condition. In some situations, analogies may also be helpful.
2. Although many fistula clients have been shunned by family members or communities, it is also common for them to have isolated themselves. For this reason, **initial counseling must often include key messages of acceptance** to help women "find their voice" again. In the words of one participant, to learn "love getting and love giving" all over again.
3. In some settings, **providers themselves may hold attitudes or beliefs that further stigmatize fistula clients.** Counseling training should include a focus on addressing providers' own biases and potential misperceptions about women who present with obstetric fistula.
4. Women who are **former fistula clients are often excellent facility- or community-based counselors.** With a small amount of training, they can become valuable messengers.
5. **Sharing stories of women who have been successfully repaired may be an important strategy in pre-operative counseling** to allay fears and provide hope when women are at an especially vulnerable point in the treatment process.
6. In situations where fistula clients speak a language different from staff, **former fistula clients can also serve as effective translators.**
7. When possible, **involving family members and/or partners in counseling** is key to a client's overall success, as they can provide critical support for the client's emotional, material, and clinical needs both pre- and post-operatively. Family members and partners may be counseled together with the client or during a separate session, depending on the information being discussed.
8. As former fistula clients begin the process of reintegration, **existing community structures and support groups can be important to ease the process of re-entering society.**
9. One key **source of empowerment that counselors can relay is the woman's role in her own recovery process.** By noting the progress of their healing and taking charge of their own care, clients often begin to acquire a sense of control over their lives again.

> **"A woman with fistula can use her damaging situation to access support which becomes her strength as she recovers."**
> —Daniel Murokora, Mulago Hospital

> **"Fistula clients who have been empowered at FORWARD have been envied by other women in their communities, to the point that one woman even said she wishes she had had a fistula!"**
> —Rahmat Hassan Mohammed, FORWARD/Nigeria

10. In order to assist another health care provider to know about a fistula client's previous repair, **some facilities have created cards that include the surgeon's notes**. The card is given to the client when she leaves the facility and she is instructed to bring it with her if/when she seeks care again. This helps the client to control the flow of medical information, relay accurate details, and "own" the experience in a way that she might not otherwise.

experts' meeting participants

Appendixes

List of Meeting Participants
Daily Objectives and Meeting Agenda
Case Studies
Focus Group Discussion Tool

Appendix 1:
List of Meeting Participants

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(continued)

Appendix 1:
List of Meeting Participants (continued)

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(continued)

Appendix 1:
List of Meeting Participants (continued)

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Appendix 2:
Daily Objectives and Meeting Agenda

DAY ONE - March 29, 2005

Objectives

- To note common myths and misperceptions about obstetric fistula
- To discuss provider concerns when working with fistula clients
- To create a shared understanding of fistula clients' needs—emotional, physical, conomic, etc.
- To craft a shared sense of priorities of what is needed to meet clients' needs
- To separate the fistula counseling priorities by sequential stages

Time	Session	Leader(s)	Notetaker
9:00-9:30	Welcome and Introductions	EH staff, meeting participants, observers	Mary Nell
9:30-9:45	Icebreaker	Erika	N/A
9:45-10:00	Review of meeting objectives, day 1 objectives, agenda, and logistics	Lauren	N/A
10:00-10:20	Discussion: Myths and misperceptions about obstetric fistula	Mary Nell	Shipra
10:20-10:45	Wheel exercise: Listening to provider concerns	Erika	Lauren
10:45-11:15	Tea break and honorarium distribution	Shipra and Lauren	
11:15-12:00	Small group discussion and report out: Building a profile of a "typical" fistula client	Feddis	Each EH staff person in small group
12:00-1:00	Card exercise to finish the statement, "Every fistula client needs…"	Mary Nell	N/A
1:00-2:00	L U N C H		
2:00-2:30	Card sorting, grouping, discussion	Mary Nell	Shipra
2:30-3:15	Small group work on categorizing pre-op needs; immediate post-op needs; later post-op needs	One person in each small group will present	Lauren
3:15-3:45	Tea break		
3:45-4:15	Small groups report back to larger group; Discussion	Henry	Lauren
4:15-4:30	Wrap up, review of progress made	Erika	Shipra

DAY TWO - March 30, 2005

Objectives

- To review progress made in Day 1
- To discuss key skills for providers who counsel
- To identify which providers can and do serve as counselors at various stages of service delivery, and to brainstorm key messages that these providers should offer during sequential stages of service provision
- To identify issues related to counseling fistula clients with special needs
- To brainstorm no or low cost ways to make changes in facilities to improve the counseling environment
- To create a list of key messages for partners, family members

Time	Session	Leader(s)	Notetaker
9:00-9:30	Review of previous day's progress, handout on client needs, Day 2 objectives, agenda, and logistics	Shipra	N/A
9:30-9:45	Icebreaker	Lauren	N/A
9:45-10:30	Counseling role play: the bad and the good	Erika	Shipra
10:30-11:00	Tea Break		
11:00-10145	• Small groups on analysis of role play and discussion; Report back • What makes an "ideal" counselor? What skills and characteristics does s/he have?	Lauren	Mary Nell
11:45-12:00	Matrix exercise: Who are the counselors? • What, if any, are specific roles of different kinds of providers who counsel women with fistula? • At what stage should key counseling messages be provided? By whom?	Shipra	Lauren
12:00-12:30	Brainstorm on special counseling needs for young clients, older women clients, clients with HIV/AIDS, and clients with special needs	Mary Nell	Erika
12:30-1:30	L U N C H		
1:30-2:30	Facility case studies; no- or low-cost ways to improve the counseling environment	Setara	Shipra
2:30-3:00	Group discussion on key messages for family members of fistula clients (for example, partner/husband, mother-in-law, etc.)	Erika	Mary Nell
3:00-3:15	Wrap up, next steps, workshop evaluation	Mary Nell	Lauren

Appendix 3:
Case Studies

Facility Case Study

Gondola Hospital is a public sector facility in a rural area with a catchment population of 2 million. The 200 bed hospital was built about 80 years ago, and has not had much renovation done to it.

There is a severe lack of space, with clients waiting on the floor, women laboring in the hallways, and other clients and their families waiting outside in the courtyard. There is a reception and intake area, but it is in the corner of a large room, rather than in a separate room. The staff member assigned to do basic intake is extremely busy and impersonal in her communications. Although the providers on staff are committed to serving women with fistula, they have a difficult time getting operating theatre time (given the other emergency cases), finding places for women to stay who are awaiting surgery, and securing bed space for them post-operatively.

The staffing pattern includes 2 local surgeons with the capacity to do fistula repair (although one is away on leave), an anesthetist who also works at 2 other hospitals in the district, 8 nursing sisters to cover the wards, 2 nurses who work in the theatre, and 4 nurse aides. None have had training specific to fistula care, and they are overstretched in terms of the numbers of clients they cover. There is a health educator who advises the community outreach team, and also is assigned to do family planning and VCT counseling. When she conducts counseling sessions, she either does it in groups or does it within earshot of clients who are waiting for other services.

Many of the clients are refugees from a neighboring country. They are very poor and usually cannot pay the small fee that the hospital requests. They also speak a language only one person on staff—a nurse's aide—can speak.

There are no family planning services within the hospital, nor are there any patient education materials (such as brochures or pamphlets), pelvic models, or posters addressing health issues.

Small Group Instructions

1. What challenges to a good counseling environment does Gondola Hospital have? Please list five.
2. Given the challenges you noted, what can existing staff at Gondola hospital do to improve the counseling environment for fistula clients for little or no cost?

Counseling Case Study

Patience is an 18-year old woman living in a remote town in Uganda. She has lived with both VVF and RVF for two years. The smell from her leaking waste bothers her husband to a point where he abandons her to find a new wife. Without any support, she is forced to return to live with her mother and siblings. Even in this new environment, she is treated badly. Her family members blame her for her situation and make her feel like a criminal. While there, she is isolated from others in the compound, forced to sleep in a small shed in the back area. She is not allowed to participate in household activities such as cooking and helping to wash clothes. She feels sad and lonely every day. She visits the local village healer who tells her that she should consume a concoction of herbs. He assures her that if she returns every few weeks to purchase the recipe from him that her condition will go away. After several months, her problem still persists. She later hears about symptoms similar to her own described on the local radio station, and it seems that these symptoms can be cured at the local district hospital. She immediately speaks with her mother about this and heads to the facility the following day. She is admitted to the hospital and is sent to speak with someone who will listen to her, and give her information about her condition and the treatment she will receive.

Methodology:

After reviewing the case study as a group, two sets of partners (one playing Patience and one playing the counselor) volunteered to role-play counseling sessions based on the above scenario. The first partners were asked to showcase a "bad" counseling session, after which the group discussed the session, based on the questions below, and determined how counseling could be improved. Following the discussion, a second client-counselor group role-played a "good" counseling session. The below questions were used again to guide an ensuing discussion on what constitutes good counseling for fistula clients.

Questions to group:

1. After viewing this scenario, what were some of the things that can be construed as good/poor counseling behavior?
2. Did this counseling experience help the client? Why or why not?
3. How do you think this client perceived the treatment she received from the counselor?
4. Do you think the counselor could have provided better counseling support to this client? If so, how?
5. Do you feel this client feels further stigmatized after this experienced? Why or why not?

Appendix 4:
Focus Group Discussion Tool

Clinical treatment questions

1. How were you treated by the staff when you went to a facility for care? How would you like to have been treated?
2. Once you got to the hospital, did anyone explain what was happening to you? (Who?)
3. Did anyone explain what would be done to you? (Who?)
4. Did anyone talk to you about how you developed this condition? (Who?)
5. Did anyone talk about how to take care of yourself after the operation? (Who?)
6. Did you have a chance to ask questions before you were discharged? If yes, were your questions answered? Did the answers meet your needs?
7. What have you learned from this experience? What changes would you make to the services you received after your experience at the facility?
8. If you were interested in getting pregnant after the operation, were you given information about how to protect yourself from getting another fistula? Did anyone tell you to delay trying to get pregnant for at least 3-6 months? How did you think you could do that?
9. Did anyone explain to you that you could have a baby after this pregnancy?

Community related questions:

10. How do people get information about fistula repair (or other health services) in your community?
    - Word of mouth from friends and family? Media sources such as the radio?
11. How are decisions about seeking care for fistula made in your community?
    - Husbands? Mother-in-laws? Religious or community leaders? Others?
12. After your operation, did any of you return to the community where you lived before you developed fistula? If not, why not?
13. Do you think teenage pregnancy is a problem in your community? Why or why not?
14. What are some problems that girls experience when they fall pregnant at a very young age?
    - What health problems do teenage girls experience during pregnancy and delivery?
    - Please tell us any stories of health problems of teenage girls during a pregnancy or delivery?
15. How did you hear about getting treatment for fistula? In your community, what are the best ways to get information about getting treatment for fistula?

Psychosocial questions

16. After your surgery, did you have any concerns about returning to your families and communities? Did anyone talk to you about these concerns?

General

17. What do you think are the biggest needs of women with fistula?
18. In addition to talking with the woman who has fistula, do you think there is anyone else that providers should talk with when giving care for fistula? (e.g., partners, family members, community leaders, religious leaders, etc.?)

Experts' meeting

We recently met with healthcare providers who work with women who have fistula, to see what they think are the important things to discuss when counseling women who have fistula, or who have undergone fistula repair surgery. Some of the things that the healthcare providers identified included: …

We are very interested in hearing from each of you, based on your own experiences, about what kinds of issues healthcare providers and counselors should address when counseling women before, during, and after fistula surgery.

19. What do you think of the ideas that the healthcare providers outlined? Do you think there's anything missing from this list?

Let's summarize some of the key points from our discussion.

20. Do any of you have any questions now?

Thank you again for your participation. Your discussion will be used to help design a book that will help providers and social workers to address the needs of women with fistula.