CARE OF GIRLS & WOMEN LIVING WITH FEMALE GENITAL MUTILATION A CLINICAL HANDBOOK



World Health Organization

# CARE OF GIRLS & WOMEN LIVING WITH FEMALE GENITAL MUTILATION

A CLINICAL HANDBOOK



Care of girls and women living with female genital mutilation: a clinical handbook

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## PREFACE

It is estimated that over 200 million girls and women worldwide are living with FGM, which can affect multiple aspects of a woman's health and well-being. Despite its high prevalence in many settings and the health consequences associated with it, many health-care providers have limited knowledge on FGM and limited skills for preventing and managing related complications. To address this gap, WHO continues to develop evidence-informed guidelines and tools to ensure that affected girls and women receive the highest quality care possible.

What's new about this publication is that it distils the evidenceinformed recommendations into a practical and user-friendly tool for everyday use by health-care providers. It covers a wide range of health topics in nine chapters, ranging from basic knowledge and communication skills to management of a range of complications. Moreover, it describes how to offer first-line mental and sexual health support as part of comprehensive care to address multiple aspects of women's health and well-being. This clinical handbook is based on the *WHO Guidelines on the management of health complications from female genital mutilation,* 2016. It also draws on other WHO publications, in particular:

- the teacher's guide and student's guide versions of *Female genital mutilation: integrating the prevention and the management of the health complications into the curricula of nursing and midwifery,* 2001;
- Eliminating female genital mutilation: an interagency statement, 2008;
- Global strategy to stop health-care providers from performing female genital mutilation, 2010; and
- mhGAP intervention guide for mental, neurological and substance use disorders in non-specialized health settings: mental health Gap Action Programme (mhGAP) – version 2.0, 2016.

## ACKNOWLEDGEMENTS

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Christina Pallitto and Karin Stein at the WHO Department of Reproductive Health and Research conceived of and led the development of the handbook under the leadership of Lale Say and lan Askew, of the same department.

Karin Stein oversaw the development of the content of the handbook with technical input from the following experts: Jasmine Abdulcadir, Owolabi Bjälkander, Tammary Esho, Lynne Jones, Comfort Momoh, Fabienne Richard, Mustapha Touré and Cendrine Vanderhoeven.

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Erica Lefstad was responsible for the design and layout of the handbook, and Jane Patten of Green Ink, United Kingdom, conducted the technical editing.

The production of this handbook was made possible thanks to the generous support of the Norwegian Agency for Development Cooperation (Norad). GUIDING PRINCIPLES FOR THE HANDBOOK This handbook is based on three important guiding principles.

- 1. Girls and women living with FGM have experienced a harmful practice and should be provided with high-quality health care.
- 2. Medicalization of FGM (i.e. health-care providers performing FGM) is never acceptable. The practice violates medical ethics because: (a) FGM is a harmful practice; (b) medicalization perpetuates FGM; and (c) the risks of the procedure outweigh any perceived benefit.
- 3. All stakeholders at the community, national, regional and international levels should initiate or continue actions directed towards primary prevention of FGM. Health-care providers in particular should play a key role in the prevention of FGM.

# ABOUT THIS HANDBOOK

This handbook is for health-care providers involved in the care of girls and women who have been subjected to any form of female genital mutilation (FGM). This includes obstetricians and gynaecologists, surgeons, general medical practitioners, midwives, nurses and other country-specific health professionals. Health-care professionals providing mental health care, and educational and psychosocial support – such as psychiatrists, psychologists, social workers and health educators – will also find this handbook helpful.

## HOW SHOULD THIS HANDBOOK BE USED?

This handbook is an easy-to-use tool that contains all the essential information you need in order to provide care to girls and women who have been subjected to any type of FGM, either recently or in the past.

### In particular, this handbook offers advice on how to:

- communicate effectively and sensitively with girls and women who have developed health complications due to FGM;
- communicate effectively and sensitively with the husbands or partners and family members of those affected;
- provide quality health care to girls and women who have health issues due to FGM, including immediate and short-term obstetric, gynaecological or urogynaecological complications;
- provide support to women who have mental and sexual health conditions related to FGM;
- identify when and where to refer patients who need additional support and care; and
- work with patients and families to prevent the practice of FGM.

## GLOSSARY AND INSTRUCTIONS ON HOW TO USE THE SYMBOLS AND VISUAL ELEMENTS CONTAINED IN THIS HANDBOOK

This handbook is organized in 9 chapters. Within each chapter, symbols and coloured elements help readers navigate the text and provide further information relevant to daily clinical practice.

### NAVIGATION

These symbols indicate that readers should go to other chapters and sections for further information.



### NOTE OF REFERRAL

Use of this blue symbol and/or boxed text signifies that a referral may be necessary.



**NOTE OF REFERRAL:** If you are seeing a female patient with severe bleeding at a secondary care facility where blood transfusion is not available, transfer her to a tertiary care facility immediately, if possible.

### **IMPORTANT!**

Use of this red symbol and/or boxed text (example below) highlights important information.

### **IMPORTANT!**

A "mandatory duty to record" means that a health-care provider is legally required to write down all cases of FGM in the girl's or woman's medical record.

### REMEMBER

Boxed text, like the example below, and side panels using the word "REMEMBER" highlight important information that readers should keep in mind during clinical practice.

**REMEMBER:** It's incorrect to assume that all girls and women from FGM-practising communities have undergone the procedure or that all women with FGM have health complications from the practice.

### NOTE ON FOLLOW-UP

Use of this grey symbol and/or boxed text indicates follow-up actions that may be necessary.



**NOTE ON FOLLOW-UP:** Ask the patient to return for daily wound care during the following seven days. If this is not possible, make an appointment for her to return after seven days to assess her progress.



### **ASSESSMENT PAGES**

Assessment pages take readers through the clinical assessment process step by step. It is important that users start at the top of the list and move through all of the steps to develop a comprehensive clinical assessment before moving on to the management phase.





### MANAGEMENT PAGES

Management pages provide step-by-step instructions on how to provide clinical care. It is important that users start at number 1 and proceed through all the steps in order, implementing all that are appropriate for your patient, as indicated.





### **FOLLOW-UP PAGES**

Follow-up pages provide detailed information on how to continue the clinical relationship and instructions for follow-up.

### ICONS

### The following icons are used throughout the handbook.





\*Some additional resources can be accesssed by scanning a quick response (QR) code.

UNDERSTANDING FEMALE GENITAL MUTILATION (FGM)

# After reading this chapter you should be able to:

- Understand what FGM is and why and where this practice happens
- Understand what is meant by the medicalization of FGM
- Understand common beliefs about FGM and know how to respond to them
- Use the correct terminology when discussing FGM with patients
- Recognize FGM as a violation of basic human rights principles

## In this chapter



# 1.1 UNDERSTANDING FGM

It is estimated that over 200 million girls and women worldwide are living with the effects of FGM. Of these 200 million, 44 million are aged less than 15 years (1).

## 1.1.1 WHAT IS FGM?

Female genital mutilation (FGM) includes all procedures that involve the partial or total removal of external genitalia or other injury to the female genital organs (such as stitching of the labia majora or pricking of the clitoris) for non-medical reasons (2). In addition to having no health benefits, FGM interferes with normal body functions and can have a negative effect on several aspects of a girl's or woman's life, including her physical, mental and sexual health and her relationship with her husband or partner and other close family members (3).

# **1.1.2 WHERE AND AT WHAT AGE IS FGM PERFORMED?**

FGM is a global concern. To date, the practice is reported in 30 countries in Africa and in a few countries in Asia and the Middle East. Some forms of FGM are also reported to occur among certain ethnic groups in Central and South America, and Eastern Europe. The rise in international migration has also increased the number of girls and women living in the various diaspora populations, including in Australia, Europe, New Zealand and North America, and who have undergone or may undergo the practice (2,4).

The age at which girls experience FGM varies across countries and cultural groups. In some communities, FGM is performed before girls turn five years old, but in others, girls are cut when they are between the ages of five and 14 years, or prior to marriage (4).

## **1.1.3 WHY DO COMMUNITIES PRACTISE FGM?**

FGM is practised for a variety of sociocultural reasons, varying from one region and ethnic group to another. Some consider it a rite of passage into womanhood. Others believe it helps preserve a girl's virginity until marriage. In most communities where it is practised, parents see it as essential to ensuring their daughter's acceptance into society. Below you will find the main reasons why communities practise FGM (3).



### **RESPECT FOR TRADITION**

FGM is often seen as part of the history and cultural tradition of the community. Community members, including the women, often support and continue the practice because they see it as a sign of respect towards the elder members of the community.

### RITE OF PASSAGE

In many cultures, FGM constitutes an important rite of passage into adulthood for girls. Often the event is marked with a ceremony and/or celebration. It may be considered a necessary step towards being viewed as a respectable adult woman.





### SOCIAL CONVENTION

Where FGM is widely practised, it is considered a social convention. Those who adhere to the practice may be better accepted in their communities, while those who do not may face condemnation, harassment and exclusion.

### ENHANCE FERTILITY

In some practising communities, women and men believe that if a woman is not cut she will not be able to become pregnant or she may face difficulties during labour.



### MARRIAGEABILITY

There is often an expectation that men will marry only women who have undergone FGM. The desire and pressure to be married, and the economic and social security that may come with marriage, can perpetuate the practice in some settings.

### ENSURE VIRGINITY, CHASTITY AND FAITHFULNESS

FGM is believed to safeguard a girl's or woman's virginity prior to marriage and ensure fidelity after marriage. Therefore, families may believe that FGM protects a girl's and her family's honour.

### **CLEANLINESS AND BEAUTY**

In some communities, FGM is performed in order to make girls "clean" and beautiful. Cleanliness may refer to the body; female genitals that are cut or closed are sometimes seen as more hygienic and beautiful, but it may also refer to spiritual purity.



The removal of genital parts that are considered masculine (i.e. the clitoris) is considered to make girls more feminine, respectable and beautiful.

### RELIGION

Some communities believe that FGM is a religious requirement, and some religious leaders may promote the practice, even though it is not mentioned in any major religious texts.









## **1.1.4 WHAT IS THE MEDICALIZATION OF FGM?**

Medicalization of FGM refers to situations in which FGM is practised by any category of health-care provider, whether in a public or a private clinic, at home or elsewhere. It also includes the procedure of re-infibulation at any time in a woman's life (5).

For more information on professional ethics and the medicalization of FGM, refer to Chapter 9.

### **IMPORTANT!**

Health-care professionals who perform FGM are violating girls' and women's rights to life, physical integrity and health.

0

Even if they feel that they can perform the practice in a safer way than a traditional cutter, or that they are doing the best thing for a girl or woman, when a health-care provider carries out FGM, they only further legitimize the practice.

They are also violating the fundamental medical ethic to "Do no harm" (3) and the fundamental principle of providing the highest quality health care possible.

## **1.1.5 TERMINOLOGY**

The term *female genital mutilation (FGM)* is used by WHO. The use of the word "mutilation" reinforces the fact that the practice is a serious violation of girls' and women's rights. This term also establishes a clear distinction from male circumcision, and emphasizes the gravity and harmfulness of the act.

The terms *female genital cutting (FGC)* and *female genital mutilation/cutting (FGM/C)* are often used among practising communities and individuals. These terms reflect the importance of using non-judgemental terminology with practising communities. Terms such as *excision* or *genital cutting* are also acceptable when discussing the topic in practising communities.

The term *female circumcision* should be avoided since it draws a parallel with male circumcision and, as a result, creates confusion between these two distinct practices (see section 1.2.3).

## CULTURAL NOTE 💭

In certain communities, some forms of FGM (usually types I and II) are called *"sunna"* to imply they are prescribed by religion. Type III FGM is often called *"pharaonic"* implying its deep cultural roots. When discussing FGM with a patient or other members of the community, you may hear these terms, but it is important to understand that different people interpret them differently and that, **regardless of the terms used, FGM is not mandated by religion.** 

# 1.2 BELIEFS ABOUT FGM AND HOW TO RESPOND TO THEM

In most FGM-practising communities, there are a number of beliefs in support of FGM that tend to influence people's attitudes to the practice. These beliefs may have been around for generations and, because most community members share them, it is difficult to challenge them, even when many of the facts are untrue. As a healthcare provider, it is important to know about such beliefs and to recognize whether they are supported by evidence or not. This section lists the most common shared beliefs about FGM and identifies whether they are true or false. It also describes the reasons why the practice should be discouraged. You can use this information when discussing FGM with women and members of their families.

## **1.2.1 BELIEFS RELATED TO CULTURAL TRADITIONS**

FALSE

FGM is a religious mandate.

FALSE

FGM is not mentioned in religious texts such as the Koran or the Bible. Moreover, many religious leaders think this tradition should end. In communities practising Islam, some people argue that there are *hadith* (a saying or action attributed to the Prophet Muhammad) that speak of FGM, and therefore they view the practice as a religious requirement. However, several eminent scholars have stressed that these *hadith* lack authenticity and cannot be used as evidence that FGM is a religious mandate (6).

If a girl is not cut, she will not find a husband and marry.

Recent surveys show that men in many communities would like FGM to end (5,7).

Girls who do not undergo FGM cannot enter womanhood and become a respectable woman.

In many cultures where FGM is not practised, girls take part in different rites of passage to mark their entrance into womanhood and become respectable members of the community.

FALSE

## **1.2.2 BELIEFS RELATED TO SEXUALITY**

FGM helps control the sexuality of women and ensure faithfulness.

## FALSE

Evidence shows that women who have undergone FGM experience less sexual desire and satisfaction (8). This can affect their capacity to enjoy a healthy and pleasurable sexual relationship with their husbands or partners, and this may prevent both partners achieving a fulfilling sexual life, thereby damaging the marital relationship (9).



FGM can cause pain during sexual intercourse for women.

Many women experience pain during sexual intercourse due to the presence of scar tissue and vaginal dryness in the genital area (8,10). In the case of type III FGM, an extremely tight vaginal opening may cause intense pain during penetration. Infibulated women also endure pain when the vaginal opening is torn or cut open to allow sexual intercourse on her wedding night and during the weeks that follow. This may cause great anxiety for the woman and her husband or partner.

### FGM can cause pain during sexual intercourse for men.

### TRUE

The presence of scar tissue in the female genital area can cause difficult and painful penetration for both partners. Research shows that some men report wounds, bleeding and infection in the penis, in addition to psychological problems (10). In the case of type III FGM, penetration is sometimes impossible if the woman is not deinfibulated. This can cause great anxiety for the couple, especially when they are attempting to start a family.

## **1.2.3 BELIEFS RELATED TO HEALTH**

If FGM is performed by a health-care professional, there is no long-term physical damage.

FALSE

FGM is a harmful practice regardless of how it is performed. Health complications can arise in the short and long term, regardless of who has performed it (5).

FGM is no different from voluntary medical male circumcision (VMMC).

### FALSE

Male circumcision is the surgical removal of the foreskin, the retractable fold of tissue that covers the head of the penis. The inner aspect of the foreskin is highly susceptible to HIV infection. Evidence shows that VMMC reduces the risk of female-to-male sexual transmission of HIV, therefore the World Health Organization (WHO) and Joint United Nations Programme on HIV/AIDS (UNAIDS) recommend VMMC as an important strategy in HIV prevention *(11)*.

If a woman is deinfibulated, the baby may fall out during pregnancy.

FALSE

The baby grows and develops inside the uterus. The lower part of the uterus, called the cervix, is responsible for maintaining the baby inside. FGM does not affect the integrity of the cervix.

# A woman who is not cut cannot become pregnant.

### FALSE

It is important to remember that women from parts of the world where FGM is not practised do become pregnant and deliver healthy babies.

FGM has health benefits for the baby.

### FALSE

There are no health benefits to FGM, neither for the mother nor for the baby. On the contrary, a study conducted by WHO found that babies born to mothers who have type III FGM are more likely to require resuscitation at birth and have a higher risk of perinatal death (12).



If the clitoris is not removed it can hurt the baby during delivery.

This is a myth. The clitoris can cause no harm to the baby or the mother. There is no evidence of this in any study.
If the clitoris is not cut it will grow until it becomes as big as a male penis.

#### FALSE

The clitoris is a female sexual organ and an important anatomical source of sexual pleasure in women. The clitoris stops growing after puberty. At this stage, its visible part – the clitoral glans – is still a small, round seed-like structure located above the opening of the urethra covered by the prepuce (13).

# 1.3 CLASSIFICATION OF FGM

WHO classifies FGM into four types, as described in this section (3).

# 1.3

## TYPE I

Partial or total removal of the clitoral glans (clitoridectomy) and/or the prepuce



Type Ia: removal of the prepuce/clitoral hood (circumcision)

**Type lb:** removal of the clitoral glans with the prepuce (clitoridectomy)

### TYPE II

Partial or total removal of the clitoral glans and the labia minora, with or without excision of the labia majora (excision)



Type IIa: removal of the labia minora only

+ +

**Type IIb:** partial or total removal of the clitoral glans and the labia minora (*prepuce may be affected*)





**Type IIc:** partial or total removal of the clitoral glans, the labia minora and the labia majora (*prepuce may be affected*)

1.3

### TYPE III

Narrowing of the vaginal opening with the creation of a covering seal by cutting and appositioning the labia minora or labia majora with or without excision of the clitoral prepuce and glans (infibulation)



#### Type Illa:





Type IIIb:

+

+ + appositioning of the labia majora

1.3

### TYPE IV

All other harmful procedures to the female genitalia for non-medical purposes, for example pricking, piercing, incising, scraping and cauterization



# **REMEMBER:**

A girl's or woman's genital cutting may not look exactly the same as that described in the WHO typology. To establish with certainty what type of FGM a patient has, you will need to perform a genital examination.

# 1.4 FGM & HUMAN RIGHTS

This handbook contains useful information on how to identify and manage the health problems that may arise from FGM. But, even if no health complications occur, a girl who has undergone FGM has still been harmed in a way that can affect her future life (14). FGM is often performed on young girls who, by law, are not old enough to make their own decisions and, therefore, provide informed consent. Although parents may believe FGM will help improve a girl's social status, in fact this procedure hurts her emotionally and physically, and its results will remain with her throughout her life.

# FGM VIOLATES A SERIES OF WELL ESTABLISHED HUMAN RIGHTS PRINCIPLES

- principles of equality and non-discrimination on the basis of sex
- right to life (when the procedure results in death)
- right to freedom from torture or cruel, inhuman or degrading treatment or punishment
- rights of the child.

As it interferes with healthy genital tissue in the absence of medical necessity and can lead to severe consequences for a girl's and woman's physical, mental and sexual health, the Member States of the United Nations have agreed to declare FGM a violation of the human rights of girls and women, including every person's right to the highest attainable standard of health (2).

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COMMUNICATING WITH GIRLS & WOMEN LIVING WITH FGM

# After reading this chapter you should be able to:

- Understand the importance of discussing FGM with your female patients
- Understand your role as a health-care provider when discussing FGM with your female patients
- Establish more effective communication with girls and women living with FGM and their family members
- Understand when and how to ask about FGM
- Discuss FGM in detail if needed
- Develop a care plan with your female patients
- Understand the importance of recording FGM
- Understand how to work with interpreters and cultural mediators
- Recognize the ethical considerations when communicating with your female patients about FGM
- Understand the meaning of "woman-centred care"
- Better understand the role of family members in the woman's decision-making process

### In this chapter



#### 2.1 THE IMPORTANCE OF DISCUSSING FGM



# 2.1 THE IMPORTANCE OF DISCUSSING FGM

FGM can cause several serious physical, mental and sexual health complications in girls and women, and in their newborn children (1). As a health-care provider, you have the unique opportunity to support and improve the health and well-being of girls and women living with FGM. This important task should be undertaken in the context of a trusting and respectful collaboration between provider and patient.

# 2.1.1 WHY IS IT IMPORTANT TO TALK ABOUT FGM WITH YOUR FEMALE PATIENTS?

Providing care and treatment requires not only understanding the woman's physical, mental and sexual health needs but also supporting her and providing adequate information so that she can make informed decisions. To achieve this, it is essential that you communicate effectively with your female patients, and that you openly discuss their health and FGM status with them in a sensitive way.

Women who have undergone FGM often delay or do not seek help when they experience health problems that may be linked to the procedure because they may be ashamed, they may not be able to access the health-care facility or they may not have money to pay for treatment (2). Another reason they may not seek care for these health problems is that many female community members have experienced similar health complications such that certain FGMrelated symptoms have become "normalized" and women do not think they are relevant to consult a health-care provider about.

On the other hand, women who do seek care for particular medical problems may not be aware that FGM has caused the problems and therefore may not spontaneously mention their experience of FGM to the care provider.

For all these reasons, discussing FGM with your female patients is extremely important.

2.1

### 2.1.2 CHALLENGES WHEN DISCUSSING FGM

Discussing FGM, and the health complications linked with the practice, can be challenging both for the health-care provider and for girls and women seeking care.

#### HEALTH-CARE PROVIDER'S PERSPECTIVE

- Health-care providers may believe that talking about FGM will remind the girl or woman of the initial trauma they have gone through, causing distress (3, 4).
- They may also think of FGM as a cultural, private or family matter, so they may fail to ask girls and women about their FGM status and possible health complications.
- Some may feel that even if they ask patients about FGM they are not prepared or formally trained to provide adequate care and support to these girls and women (2).
  - They often do not have sufficient time during the consultation to discuss FGM in detail and therefore avoid asking about the topic.

#### PATIENT'S PERSPECTIVE

- Many girls and women may feel FGM is a private matter and that discussing it with a health-care provider is uncomfortable or even embarrassing, particularly when the health-care provider is male (3).
- Some girls and women may not feel confident that a health-care provider is sufficiently familiar with FGM and may therefore think the provider will not provide competent care and management of FGM-related health complications.
- The girl or woman may be in pain or she may be experiencing an emotionally difficult situation that does not allow her to communicate openly.
- Some girls and women may fear they will be judged or blamed for the FGM and/or the health complications they have experienced.
- In some countries, people may be aware that the practice is illegal, and therefore girls and women may fear they will be sanctioned for supporting or undergoing the procedure if they speak openly about it.
- Girls and women may worry that the community will view them as breaking cultural rules if they confide in outsiders about FGM (4).

# 2.1.3 WHAT IS MY ROLE AS A HEALTH-CARE PROVIDER?

Your role as a health-care provider is to support girls and women who seek care at a health-care facility, provide them with the best clinical care possible and avoid causing them further harm. As a health-care provider, every contact with a girl or woman who has experienced FGM represents an opportunity to provide her with accurate information about her body and health.

WHO BEST PRACTICE STATEMENT

Health-care providers have the responsibility to convey accurate and clear information, using language and methods that can be readily understood by clients (1). Very importantly, you are in a unique position to influence and change attitudes about FGM and about women's bodies and rights, you can also assist with the decision-making process about whether a girl or woman needs to seek further care, and you can play an important role in helping women and girls speak openly about their needs (5). Changing attitudes about FGM is a key step towards preventing new cases of FGM in the community.

Building your communication skills so that you are able to discuss FGM with **empathy** and in a non-judgemental manner will help you to fulfil your role as health-care provider, as described above.



**Empathy:** The ability to identify with or understand the perspective, experiences or motivations of another person and to comprehend and share another person's emotional state.

# 2.2 BASICS OF EFFECTIVE COMMUNICATION

Effective communication requires a two-way dialogue between the health-care provider and the patient (5). This means that during the conversation both participants will listen and provide information to each other. In an ideal situation, the patient will initiate this dialogue by explaining the reason for seeking health care or counselling. However, in reality, especially with a sensitive topic such as FGM, you may need to initiate the conversation yourself by asking a few open-ended questions and creating a safe space in which the girl or woman can freely express her views and needs regarding her own health and well-being.

## ESTABLISHING EFFECTIVE COMMUNICATION

Establishing effective communication will go a long way towards ensuring that the patient is provided with the highest quality care (5). Following are some suggestions to help you have an effective dialogue about FGM with a female patient.



#### CREATE A WELCOMING ENVIRONMENT

Make sure the dialogue takes place in a comfortable and welcoming environment where the girl or woman feels safe and at ease.

#### STAY OPEN TO OTHER HEALTH ISSUES

Keep in mind that not all women living with FGM have health complications related to the practice. Girls and women with FGM are also likely to seek care for health issues that are not related to FGM, in which case discussing FGM should not be the main goal of the consultation.



#### REMEMBER THAT FGM IS ONLY ONE ASPECT OF THE GIRL'S OR WOMAN'S LIFE

Other than her specific reason for coming in to seek health services, always also consider other physical, emotional or social needs for which she may require support and care prior to discussing FGM in detail. For example, she may have recently fled an area of conflict or war, lost a close family member or suffered violence or sexual abuse.

2.2

#### USE APPROPRIATE LANGUAGE AND TERMINOLOGY

Always use a language that the woman speaks (you may need to bring in an interpreter; see section 2.4 in this chapter) and ensure you use terminology she will be familiar with.  $\rightarrow$  2.4

Avoid using complex medical terms (for more information on terminology see Chapter 1).  $\bigcirc$  1



# ENSURE PRIVACY AND CONFIDENTIALITY AT ALL TIMES

Given the private and sensitive nature of FGM, most women will not want information about their FGM status to be public knowledge and therefore will not want to mention or discuss FGM in a public place such as a reception area (5). Also, your female patient has the right to confidentiality.



Once you have established, in private, that she has undergone FGM, always make sure you handle the consultation with professionalism and discretion.



Ask the woman whether she wishes to have a one-on-one private discussion with you or whether she would prefer someone else to be in the room as well, particularly if she is not comfortable being alone with a male provider.



Make sure details about her FGM status are only recorded inside the medical record and are not visible on the cover or first page. (2)
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#### PAY ATTENTION TO YOUR BODY LANGUAGE

When the girl or woman enters the room, greet her warmly and make sure you maintain eye contact when talking to her.

Avoid at all times inappropriate facial expressions, such as shock, disgust or dismay.

Be aware of and sensitive to culturally appropriate norms relating to communication and personal space. The appropriate physical proximity between you and a female patient will vary from culture to culture. In some settings, sitting in chairs near each other rather than remaining seated behind a desk may be appropriate and may help minimize the feeling of a barrier between provider and patient. Be aware that getting too close to your female patient could be interpreted as threatening in some settings, while being too far away could give the impression that you are disinterested.

#### USE A PROFESSIONAL YET FRIENDLY TONE

When discussing FGM, make sure the girl or woman feels safe.

Let the patient know that you are familiar with FGM and comfortable dealing with any issues related to the practice.

Avoid whispering (as if the subject were shameful), and avoid expressing pity or disapproval for the girl or woman (5).





#### LISTEN ATTENTIVELY AND ALLOW THE WOMAN TO SPEAK

Your role as a health-care provider is to guide the discussion by asking questions and then listening attentively, allowing the woman to speak and express herself.



Avoid providing too much information during the first encounter – sometimes too much information can reduce the likelihood of good communication.

Check that you have understood what the woman has told you by asking questions throughout the interview, as appropriate. You should avoid interrupting her, however, or correcting what she has said.

#### DO NOT JUDGE THE WOMAN OR HER CULTURE OF ORIGIN



Offering support and care to girls and women living with FGM includes acknowledging the fact that they have experienced a harmful practice and should be provided quality health care, and also validating their feelings about this. Make sure you do not judge the woman for undergoing the procedure and let her know that your role is to offer her any support she may need.

# **PAY ATTENTION TO PARENTAL ATTITUDES**

When caring for girls who have undergone or are at risk of FGM, it is important to assess whether her parents hold similar or discordant views on FGM and what those views are.





#### SHOW CULTURAL AWARENESS AND RESPECT

Remember that FGM is a deeply rooted cultural practice and that many practising community members, both male and female, may not see it as negative.

Provide information in a respectful and professional manner.

Show your patient genuine respect – she will be more likely to trust and talk to you, and accept your advice.

# 2.3 ETHICAL CONSIDERATIONS

Patient confidentiality, consent and choice are all aspects of ethics that need to be considered when communicating with girls and women living with FGM (3).

## PATIENT CONFIDENTIALITY

Patient confidentiality must be respected at all times. It is your obligation to adhere to this ethical principle. It is important that you verbally reassure the girl or woman that absolutely nothing she says will be communicated to anyone else without her agreement, including her family members. She should be told that her medical record will only be shared with other health-care professionals if this is strictly necessary, and they will also be obliged to respect her confidentiality. Knowing this may help relieve the patient's fear and anxiety when talking about what she has experienced.

### CONSENT

It is a general legal and ethical principle that valid consent must be obtained before providing a person with personal care, starting any medical treatment or conducting any physical examination. This principle reflects the right of patients to determine what happens to their own bodies, and is a fundamental part of good practice. Therefore, before carrying out any clinical actions or procedures – e.g. measuring blood pressure, vaginal examination, surgery – you must explain to the girl or woman what you are about to do and obtain her agreement. It is her right to refuse. A health-care provider who does not respect this principle may be liable both to legal action by the woman and to action by their professional body.

### CHOICE

As a health-care provider, you are required to provide a range of options for how your patient's medical condition can be handled. This requires describing what treatment options are available and explaining the advantages and disadvantages of each option. This will allow the woman, or the girl's parents/guardians, to make an informed decision.

# **REMEMBER:**

If possible, make sure all consent forms are written in the local language and include terminology the woman (and her husband where appropriate) or parents/guardians are familiar with. If language barriers exist and a translated form is not available, make sure informed consent is obtained in the presence of a trained interpreter.

# 2.4 WORKING WITH INTERPRETERS & CULTURAL MEDIATORS

When providing care to girls and women living with FGM who are outside their country of origin, a trained interpreter or cultural mediator may be required to facilitate communication. Even if your female patient understands a few words of the local language in your country or community, basic understanding of the language may not be enough to fully understand the details of the consultation on FGM or to allow her to ask questions and express what she would like to say (4).

# CONSIDERATIONS WHEN WORKING WITH INTERPRETERS AND CULTURAL MEDIATORS

- Family members should not be used as interpreters (4, 5, 6). This includes the woman's husband or partner, her children and her mother-in-law.
- It is preferable to work with female interpreters and cultural mediators, given the sensitive nature of the topic (4,5).
- If possible, the interpreter or cultural mediator should be a professional or trained interpreter or mediator (5, 6). If a trained interpreter or mediator is not available, it is recommended that you ensure that the person selected has had a separate session to discuss FGM, and that she understands the topic and related issues in sufficient detail.
- Before the interpreter or mediator undertakes the work during a patient consultation, explain to her that her personal perceptions or prejudices should never influence the conversation. It is important to ensure that the interpreter or mediator does not support FGM (4).
- The importance of confidentiality should be explained to the interpreter or mediator. Asking her to sign a written agreement can help ensure confidentiality is respected.
- If you use an interpreter or mediator, document this in the woman's medical record.
- If in-person interpretation is not possible, the use of telephonic and/or video interpretation may be considered.



#### IMPORTANT!

Make sure you ask the girl or woman if she is comfortable with the assigned interpreter or mediator.

# 2.5 WOMAN-CENTRED CARE AND THE ROLE OF FAMILY MEMBERS

The care and support you provide to a woman should always be determined by her wishes. This means that you should promote her autonomy and provide her the opportunity to make informed decisions about her care and treatment. This is also known as "woman-centred care" (7).
## WOMAN-CENTRED CARE

Women are closely linked to their social and family environments, however, and in some cultures, a woman's decision-making is expected to involve members of the family, especially her husband/ partner or female relatives. These family members may consider it their duty to be present during the consultation about FGM and to participate during the development of a care plan. This is often seen as an important way of supporting or protecting the woman. It should not, however, interfere with her care.

It is important to recognize that women often feel torn between honouring the sociocultural values and expectations of their families and/or communities regarding the management of FGM, and pursuing their own preferences for alternative management or treatment. Some women may even fear repercussions if they go against their family's wishes, especially if they are dependent on their family for social or financial support.

Therefore, while the woman's wishes should always prevail, it is important that you understand that others may have a direct influence on her choices.



**Autonomy:** The ability to make informed choices, free of coercion, based on one's own personal beliefs and values.

A good way to establish if the woman wishes to decide individually or involve other family members is by asking her in private and to clearly document her decision in the medical record. Let her know that she has the right to decide for herself. Support her decision whatever it is (5).

## If she prefers to decide on her own:

In a friendly tone, you can inform a family member that you will need a few minutes with the woman. This can be phrased as:

> You would be really helping [name of the girl/woman] if I could discuss her medical history with her alone.

## If she wishes to involve her family:

Let her know that you can call her family members at any moment during the consultation or even when it has ended; it is up to her to decide when. Once she has decided, you will invite them to enter the room, and you will present to them the agreed care plan in a positive light, protecting her confidentiality. For example, you could say:

> [Name of the girl/woman] will be so much healthier and happier when we have [whatever action the woman has selected]. It will be good for the whole family.

## **REMEMBER:**

Involving the partner and/or family in the care of the girl or woman can be a positive opportunity to empower and engage the whole family.

# 2.6 THE CONSULTATION: WHEN AND HOW TO DISCUSS FGM

OPENING THE CONVERSATION: ESTABLISHING THE BASIC FACTS

**DISCUSSING FGM IN DETAIL** 

PROVIDING INFORMATION AND DEVELOPING A CARE PLAN

**CLOSURE AND FOLLOW-UP** 

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Many health-care providers are not sure when and how they should ask about FGM. In this section, you will find a step-by-step guide on when and how to conduct a conversation about FGM with your female patients. The consultation has been divided into four parts for practical purposes. However, in reality the structure of the coversation may not follow this order.

#### OPENING THE CONVERSATION: ESTABLISHING THE BASIC FACTS

During the first consultation with a woman, the best way to establish if she has undergone FGM is by asking her directly at some point in the conversation. You may want to open the dialogue by asking the woman where she is from and where she was born. This can help you determine if she comes from a country or region in which FGM is practised.



**IMPORTANT!** It's incorrect to assume that all girls and women from FGM-practising communities have undergone the procedure or that all women living with FGM have health complications from the practice.

2.6

#### WHEN SHOULD I ASK ABOUT FGM?

Including a question about FGM status during routine historytaking will help you identify girls and women who have undergone genital cutting (5). Ask the patient about her FGM status in a neutral tone and include it among other routine questions, not in isolation and not as the first question.

- A good moment to ask about FGM is when asking the patient about past surgical interventions or current or previous gynaecological conditions.
- If you are going to perform a gynaecological examination, you can ask the girl or woman about FGM prior to examining her.

## cultural note $\mathcal{Q}$

Different cultures and communities will use different terms when referring to FGM.

Once you have asked your patient about her FGM status, you can take the opportunity to ask her which term she prefers to use when discussing FGM and use it during the consultation.

It is convenient to have at hand a list of terms commonly used to describe FGM by people from communities or other countries that visit the healthcare facility on a regular basis.

#### HOW SHOULD I ASK ABOUT FGM?

Here are some ideas for how you can ask about FGM. You could say:

Do you know if you have been cut in the genital area?

Is there anything special I need to be aware of? For example, any cultural or ritual practice or procedure that may have been performed on your genital area?

Some women from your community/country have experienced genital cutting. Can you tell me if you have been cut/closed in the genital area?



**IMPORTANT!** Depending on how old the girl or woman was when she underwent FGM, she may not recall the event at all, and she may not even know or be sure whether or not she has undergone the procedure and therefore may not report it if asked. If later during a pelvic examination you establish that she has undergone FGM, make sure you discuss these findings with great sensitivity and do not judge her for not disclosing her FGM status during history-taking.

# A B G D

### DISCUSSING FGM IN DETAIL

Once you have established that the girl or woman has undergone FGM, it is important to evaluate if, when and how you should further discuss FGM in detail. Detailed discussion will only be necessary on certain occasions. Asking yourself the following two questions will help you decide if and when you need to further discuss FGM with the girl or woman.



#### QUESTION #1: Do I need to further discuss FGM in detail?

It is important to further discuss FGM whenever your clinical judgement tells you that the girl's or woman's FGM status may affect her health and well-being. It is also important to discuss FGM when you consider that as a health-care provider you could play a role in preventing new cases of FGM.

**REMEMBER:** It is inappropriate to pursue questioning only to satisfy personal curiosity (5). Your questions should inform your treatment and follow-up plans for the patient.

The following are some examples of situations when further discussing FGM would be appropriate once you have established that the girl or woman has undergone the procedure.

- The girl or woman's clinical condition is related to FGM. In this case you must explain the situation to her and discuss a care plan (5).
- The girl or woman has specifically come to discuss FGM with you and would like to receive more information about the topic.
- She is planning her wedding.



Discussing FGM should not be rushed. Make sure you have enough time to explain things carefully and answer any questions the girl or woman may have.

- She is planning a pregnancy or is currently pregnant and has type III FGM. See Chapter 5 for more information. →5
- She is pregnant and has come for an antenatal care visit.
  See Chapter 5 for more information. → 5
- She has recently given birth to a baby girl.
- She has undergone FGM and has consulted you about mental health or sexual health problems. See Chapter 7 and Chapter 8.
  7 3



#### QUESTION #2

#### Is she ready to talk about FGM?

Since effective communication requires a two-way dialogue, once you've decided that you should further discuss FGM with the girl or woman, it is important that you determine whether or not she is ready to talk about it with you. This may not always be easy to evaluate.

- It is important to use your judgement, follow the girl or woman's lead and closely monitor her comfort level (5).
- Make sure there are no language barriers; offer to call in (or arrange an appointment that will include) an interpreter or cultural mediator, if needed.
- Let the girl or woman know that you are available to talk but that you will not insist on discussing the topic if she is not ready (5).

#### WHAT IF... she is not ready to talk to me about her FGM?

- Give her time.
- Probe more to find out what her fears and anxieties are.
- Encourage and reassure her, and make another appointment.
- Reassure her about confidentiality.
- Provide her with alternative sources of information such as websites or local organizations.
- Ask her if she would be willing to speak to another staff member instead.

#### HOW TO START THE CONVERSATION ABOUT FGM

Once you have determined that FGM needs to be further discussed and that the girl or woman is ready and willing to discuss it with you, you can begin the conversation.

Remember that your role as a health-care provider is to guide the discussion by asking questions and then listening attentively, allowing the girl or woman to speak and express herself. This requires skill. Using statements and open-ended questions can help. An open-ended question is a question that cannot be answered with "yes" or "no".

To begin discussing FGM in more depth, you could start the conversation with a general statement before asking more specific questions (5). For example, you can say:

I have read/heard that FGM is practised in your community/country.

This statement can be followed be a non-personal question that will not require her to give her personal opinion, such as:

How does your community view FGM?

How do girls/women see FGM in your community/ where you come from?



#### WHAT IF... there is no time to discuss FGM in detail?

- Try to build trust over multiple visits.
- Invite the woman or family members to return for a consultation entirely dedicated to discussing FGM in detail.

#### WHAT IF... she starts to cry?

- Give her time to do so.
- You can say, "I can't imagine how difficult it must be to talk about this. You can take your time."
- Offer her time out to take a break.

#### **REMEMBER:**

- Explain to the woman that you will take notes and that they will be kept confidential.
- Tell her that the documentation of information ensures that her situation is understood and that she won't need to repeat details which are already known and which may be upsetting to speak about.

# A-B-C-D

## PROVIDING INFORMATION AND DEVELOPING A CARE PLAN

Once you have talked with the girl or woman about her experience of FGM and any related health issues, you will need to give her information about the different treatment options and develop a care plan.

- Explain to your patient that you will give her a range of options including the different kinds of help and treatment that are available.
- Describe what types of treatment and support are available for her, and what the considerations and consequences might be for each option, including availability, cost, outcomes, recovery time, side-effects, etc. At this stage the woman should know all of her options. Assess her receptivity to receiving care and/or referral. This will help you adjust the care plan if needed.
- Some treatment options, such as deinfibulation in an unmarried girl or woman, may be considered to be culturally unacceptable in certain communities. Let her know that you understand this and support her in finding ways of overcoming these potential barriers if she selects such an option.
- Check that she has understood well what was discussed and make sure you know what her expectations are regarding the outcomes of the consultation and any treatment. This will avoid any potential misunderstandings.

#### WHAT IF... a treatment option is culturally unacceptable?

- When developing a care plan, openly discuss the potential cultural implications of certain treatment alternatives.
- Help her identify and reach out to someone close who could support her in upholding her decision within her family and/or community. This could be her husband/partner or a close relative or friend.

## **REMEMBER:**

#### Respect your patient's decision.

The woman's wishes determine the care that you give. She may want more time to think over her treatment options, and she may prefer to take an expectant approach and/or discuss other alternatives. You can guide her with additional information and referrals, if needed, but it is important that you respect her decision and do not pressure her. If your patient is a minor, you must discuss this with her parents/guardians. **A-B-C** 

#### **CLOSURE AND FOLLOW-UP**

Before bringing the consultation session to an end, you should do a brief recap and check if the woman – or the parent(s)/guardian(s) in the case of a minor – has understood everything and if she has any additional questions or requests. She may need more time to decide about her treatment options or she may need to be referred to another professional.



**NOTE ON FOLLOW-UP:** Often, more sessions will be needed before an action plan can be developed. *If follow-up is needed*, develop a follow-up plan with the patient.

## **REMEMBER:**

Take notes during and after your discussion.

It is important to take notes during and immediately after your discussion with the woman in order not to forget or miss details – human memory is not always reliable! During a deeply emotional exchange you can stop writing temporarily in order make her feel cared for and safe.

# 2.7 RECORDING FGM IN THE PATIENT'S MEDICAL RECORD

Recording when female patients have undergone FGM is part of good medical practice. Most importantly, the documentation in the patient's record will alert other health-care providers about a woman's FGM status. This may avoid unnecessary genital examinations in the future as well as improving her ongoing care.

**IMPORTANT!** A "mandatory duty to record" means that a health care provider is legally required to write down all cases of FGM in the girl's or woman's medical record. Make sure you are informed if this is legally required in your country.

# HOW DO I TELL WHICH TYPE OF FGM THE WOMAN HAS UNDERGONE?

While the WHO classification of FGM is precise, the performance of the genital excision frequently is not. FGM is usually carried out under conditions that do not allow accurate cutting. For example, the girl may struggle and move during the procedure due to intense pain, or the cutting instruments may be dull and cause tearing of the flesh rather than a clean incision. As a result, a girl's or woman's genital cutting may not look exactly the same as that described in the WHO typology (see Chapter 1). I This can make the identification and recording of FGM challenging (5). In the case of young girls, anatomical structures such as the labia are less prominent and there is little subcutaneous fat on the vulva, which can make it difficult for health-care providers to identify the girl's FGM status and type. To establish with certainty what type of FGM a patient has undergone, you will need to perform a genital examination.

# HOW SHOULD I RECORD FGM IN THE MEDICAL RECORD?

When documenting FGM in a patient's record, always note if the type of FGM was determined through a genital examination or by the patient's report. If after performing a genital examination you cannot determine exactly the type of FGM your patient has undergone, you should at least record that she has undergone FGM and describe which anatomical structures have been removed or damaged. For further information regarding the visual recording of FGM on the medical record, see section 5.2.4, in Chapter 5.

2.7

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Chapter 2 | Communicating with girls & women living with FGM



IMMEDIATE & SHORT-TERM PHYSICAL COMPLICATIONS ARISING FROM FGM

# After reading this chapter you should be able to:

- Identify the immediate and short-term physical complications arising from FGM
- Take a history and perform a clinical examination to assess such immediate and short-term physical complications
- Manage girls and women who have suffered immediate and short-term physical complications due to FGM
- Refer girls and women for further management to the next level of care

#### In this chapter



3.1 OVERVIEW OF THE IMMEDIATE & SHORT-TERM PHYSICAL COMPLICATIONS



# OVERVIEW OF THE 3.1 IMMEDIATE & SHORT-TERM PHYSICAL COMPLICATIONS

**IMPORTANT!** Most patients who present with immediate and shortterm health complications arising from FGM must be treated without delay, especially those with life-threatening conditions such as severe haemorrhage, haemorrhagic shock and/or septicaemia.

## IMMEDIATE AND SHORT-TERM PHYSICAL HEALTH COMPLICATIONS OF FGM

These include:

- severe pain and injury to tissues
- haemorrhage (severe haemorrhage can lead to anaemia)
- haemorrhagic shock
- infection and septicaemia
- genital tissue swelling
- acute urine retention.

All girls and women who undergo FGM will suffer some form of negative health consequences associated with the practice, such as intense pain, varying degrees of genital tissue damage, and psychological distress. Some girls and women will experience immediate and short-term health conditions that require rapid medical treatment.

Probably, only the most severely affected girls and women will seek health services for these complications. You are most likely to see health complications resulting from FGM in girls of the appropriate age, in the range within which cutting is traditionally practised in your country or region.

# ASSESSING THE 3.2 IMMEDIATE & SHORT-TERM PHYSICAL COMPLICATIONS

To assess the immediate and short-term physical health complications of FGM, you will need to take the patient's history and perform a clinical examination (2). COMMUNICATING IN EMERGENCY SITUATIONS

If the patient has a life-threatening condition or she is unconscious or unable to communicate, you may not be able to obtain her history nor explain that you will perform a clinical examination.

#### CHILD PATIENTS

When a child presents with acute complications, she may be frightened and unable to communicate directly.

#### **IMPORTANT!**

Because FGM is often performed on minors, the immediate and short-term physical consequences of the practice will frequently affect young girls and even babies. Minors will usually be brought to the health-care facility by their parents or family members, or by the person who performed FGM. As a consequence, and because FGM is illegal in several countries where it is practised, individuals accompanying the minor may not immediately disclose that her health condition is related to FGM.

When possible, address the girl or woman directly while also informing accompanying family members about her care.

### DOCUMENTATION

It is very important to document everything carefully in the patient's medical record.



### 3.2.1 TAKING A HISTORY

In an emergency situation, there may be insufficient time to obtain a detailed medical history. In this case, aim for a limited but focused history from the patient or her family members. This will guide the physical examination and help you reach a correct diagnosis. You can work through the following steps.

**Introduce** yourself to the patient and her family members.



Ask your patient about her presenting complaint. Gain as much information as possible about it.

If you suspect that your patient's health condition is due to FGM, ask her tactfully about any procedures she has had, including FGM. Use terminology that is familiar to her.

Ask her or her accompanying family members if she/they would like to share any information about her health and any problems she may have due to FGM.

### Reassure...



Reassure her that you are comfortable dealing with her condition and that her FGM status is not a barrier and will not prevent her from accessing health services.

## Listen...

 Let the girl or woman express her feelings and give you the information she wants to share. If she starts crying, be patient and give support.

Listen carefully and show empathy and concern. Let her know you can help her.

Once it has been established that the girl or woman has undergone any type of FGM, this information and the subsequent clinical examination should be handled with professionalism and discretion.

## Record... 🗧

8

The information (the type of FGM and the complications) should be recorded as required by the policy of the health-care institution.



**IMPORTANT!** As a health-care provider, you must always record all relevant information in the patient's medical records. However, the duty to report a minor who has undergone FGM to the legal authorities or child protection services will depend on national laws on child abuse and protection. For more details, see Chapter 9.  $\rightarrow$  9



# **3.2.2 PERFORMING A CLINICAL EXAMINATION** (2)



Ensure privacy and confidentiality.

If the patient is alert, explain to the girl or woman that you will examine her and that this will include a genital examination.

**If she is unconscious** and a family member is present, **explain** to the family member what you are about to do.



3

Ask her to lie on her back with her legs apart and knees bent.

Expose the necessary area for inspection and examination. Cover the patient until you are ready for the examination.

Wash your hands thoroughly 5 and put on gloves.

Expose and inspect the external genitalia.

3.2



# MANAGEMENT OF 3.3 SEVERE PAIN & TISSUE INJURY

The clitoris and surrounding genital tissues have a dense nerve supply and so are particularly sensitive. FGM is usually performed without anaesthetic and therefore causes severe pain (3). The pain is usually immediate, and can be very severe indeed.

## HOW SHOULD IT BE MANAGED?

Severe pain and injury associated with FGM is managed in the same way as pain and tissue injury caused by any trauma. Observe the following procedure.

**Assess** the severity of the pain and injury.

If an intravenous line is available, secure venous access.

**Give strong analgesics**, intravenously if possible, and treat the injury.

**Clean the site** with antiseptic and advise the patient or her attendants to keep it clean and dry.

5

If the patient is showing symptoms of haemorrhagic shock, treat appropriately (see section 3.5).

#### **NOTE OF REFERRAL**

• If there is no relief from pain, refer the patient to the next level of care.

• If there is extensive injury to the tissues, refer the patient for surgical repair of the injury.

• During the referral, keep the patient well sedated until she reaches the next level of care.

## MANAGEMENT OF 3.4 HAEMORRHAGE

Excision of the clitoris may involve cutting the clitoral artery, which contains blood flowing under high pressure (4). Cutting the labia also causes damage to blood vessels. Bleeding usually occurs during or immediately after the procedure. Secondary bleeding may occur after the first week if infection causes sloughing of a clot over the artery.
#### HOW SHOULD IT BE MANAGED?

Severe bleeding associated with excision is managed in the same way as severe bleeding resulting from other circumstances.

Assess the seriousness of the bleeding and the condition of the girl or woman by checking and recording her vital signs.

If the bleeding is serious and an intravenous line is available, secure venous access.

- **Inspect** the site of the bleeding.
- Clean the area with antiseptic.



Continue assessing the condition of the patient by checking and recording her vital signs every 15 minutes.

the bleeding by packing with a sterile gauze pad.

Apply pressure at the site to stop

If the bleeding is not serious, advise the patient and her attendants to keep it clean and dry.

If the girl or woman is suffering from haemorrhagic shock, treat appropriately (see section 3.5).

**If necessary, replace lost fluids.** If you are managing the patient at a primary health-care facility, give intravenous fluids and monitor her condition. Transfer her immediately to a secondary care facility for blood transfusion if necessary.

**Prescribe vitamin K** if this is the policy of the health-care institution, especially in the case of babies.

**NOTE OF REFERRAL:** If you are seeing a female patient with severe bleeding at a secondary care facility where blood transfusion is not available, transfer her to a tertiary care facility immediately, if possible.

10 A traditional dressing (e.g. containing ash, herbs, soil and cow dung) may have been applied to the wound, and these compounds can lead to tetanus or other infection. In such cases, **give tetanus toxoid and antibiotics**, in accordance with national guidelines.

**NOTE ON FOLLOW-UP:** Make an appointment for the girl or woman to return so you can check her progress. Severe bleeding can lead to **anaemia**. If anaemia is suspected, if possible, send a blood sample for haemoglobin (Hb) and grouping to assess the severity of anaemia. If anaemia is mild, give folic acid and iron tablets and advise on eating a nutritious diet. If anaemia is severe, refer for blood transfusion.

### **IMPORTANT!**

Haemorrhage is the most common and life-threatening complication of FGM.

## MANAGEMENT OF 3.5 HAEMORRHAGIC SHOCK

Haemorrhagic shock occurs when there is a reduced volume of blood circulating in the body due to severe bleeding. In the case of FGM, severe damage caused to the genital tissues can lead to excessive blood loss. Death can occur within a relatively short time if the patient fails to receive adequate treatment. HOW SHOULD IT BE MANAGED?

Haemorrhagic shock associated with FGM is managed in the same way as the condition occurring under any other circumstances. Observe the following procedure.

If an intravenous line is available, secure venous access.

**Treat for shock** by raising the patient's extremities above the level of her head to allow blood to drain to the vital centres in the brain.



Assess the severity of shock by checking and recording vital signs every 15 minutes.

**Give intravenous fluids.** If an intravenous line is not available, fluids may be given rectally.

Cover the girl or woman to keep her warm.

If she is having difficulty breathing, administer oxygen.

Have a resuscitation tray nearby.

Continue to check vital signs regularly.

**NOTE OF REFERRAL:** If you are seeing a female patient with severe bleeding at a secondary care facility where blood transfusion is not available, transfer her to a tertiary care facility immediately, if possible.

# 3.6 INFECTION AND SEPTICAEMIA

Infection may occur when FGM is conducted in unhygienic surroundings and with dirty instruments, and if there is a lack of proper wound care following the procedure. The girl or woman will present with an elevated body temperature and a dirty, inflamed wound (3).

### HOW SHOULD IT BE MANAGED?

Infection and septicaemia following FGM should be managed in the same way as when these conditions result from other causes.

**Measure and record** the patient's temperature. This will be useful for assessing her progress during treatment.

**Inspect** the vulva carefully for signs of an infected wound, and check for anything that might be contributing to the infection, such as obstruction of urine.

**If you suspect septicaemia**, take a blood culture before starting intravenous antibiotic treatment.

Take a vaginal swab (or swab from the infected wound) and a urine sample to test for the presence of infection and to identify the organisms involved.

Any obstruction (of urine) found should be removed, and the patient treated with antibiotics and analgesics.

If the wound is infected, it should be cleaned with antiseptic. Apply a sterile gauze dressing and advise the girl or woman to keep it dry.

If infection persists, refer the client to a secondary facility.

 $\rightarrow$ 

**NOTE ON FOLLOW-UP:** Ask the patient to return for daily wound care during the following seven days. If this is not possible, make an appointment for her to return after seven days to assess her progress.

## MANAGEMENT OF 3.7 GENITAL TISSUE SWELLING

Cutting and damaging the genital tissues causes a local inflammatory response. Genital swelling may also be caused by an acute local infection (2).

### HOW SHOULD IT BE MANAGED?

Observe the following procedure.

- Carry out an assessment to determine the cause of the swelling.
- **Inspect** the vulva carefully for signs of an infected wound, and check for anything that might be contributing to the infection (see section 3.6). → 3.6
- If you diagnose an inflammatory response to the cutting, give anti-inflammatories, intravenously if possible, and treat the site of injury.
- If the patient is unable to pass urine, install a Foley catheter (see section 3.8).



## MANAGEMENT OF 3.8 ACUTE URINE RETENTION

Urine retention may be the result of injury, pain and fear of passing urine, or occlusion of the urethra during infibulation. Acute retention of urine usually occurs due to genital tissue swelling and inflammation around the wound (2).

### HOW SHOULD IT BE MANAGED?

Observe the following procedure.

Carry out an assessment to determine the cause of the urine retention.

Use appropriate nursing skills and techniques to **encourage the girl or woman to pass urine**, such as turning on a water tap.

If she is unable to pass urine because of pain and fear, give her strong analgesics and personal encouragement and support.

**If she is still unable to pass urine, install a Foley catheter.** Leave the catheter in place for two to three days.

If her inability to pass urine is due to infibulation, open up the infibulation after counselling the patient and/or a family member and obtaining consent (see Chapter 6).

**NOTE OF REFERRAL:** *If urine retention is due to injury to the opening of the urethra, refer the patient for surgical intervention under anaesthetic.* 

### References

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Chapter 3 | Immediate and short-term physical complications arising from FGM



### GYNAECOLOGICAL & UROGYNAECOLOGICAL CARE

## After reading this chapter you should be able to:

- Identify long-term gynaecological and urogynaecological health complications and conditions arising from FGM
- Take a history and perform a clinical examination to assess such health complications and conditions
- Manage female patients who have suffered such health complications and conditions
- Refer girls and women to the next level of care for further management
- Discuss suitable contraceptive methods with your female patients
- Discuss cervical screening with your female patients



## OVERVIEW: 4.1 GYNAECOLOGICAL & UROGYNAECOLOGICAL HEALTH CONSEQUENCES OF FGM

As discussed in Chapter 3, the removal of or injury to healthy genital tissue can cause immediate and short-term health complications to girls and women who undergo FGM, which often require immediate medical care. However, FGM can also result in health complications and conditions that appear months or even years after the genital cutting took place. These negative health consequences usually, although not exclusively, affect the female genito-urinary system, i.e. affecting the urinary system and/or the reproductive system.

### GYNAECOLOGICAL AND UROGYNAECOLOGICAL COMPLICATIONS AND CONDITIONS ARISING FROM FGM

These include:

- chronic vulvar pain
- clitoral neuroma
- reproductive tract infections
- **menstrual problems** such as dysmenorrhoea (painful menstruation) and difficulty in passing menstrual blood
- urinary tract infections, often recurrent
- painful or difficult urination
- epidermal inclusion cysts and keloids in the genital area (1).

#### **IMPORTANT!**



Health-care providers should always consider that gynaecological and urogynaecological health complications in girls and women living with FGM may be associated with conditions other than genital cutting. These conditions should be investigated and treated according to local protocol or national guidelines. ASSESSING THE 4.2 LONG-TERM GYNAECOLOGICAL & UROGYNAECOLOGICAL HEALTH CONSEQUENCES OF FGM

> Health-care providers working in regions where FGM is performed and those seeing patients from these regions should always include direct questions about FGM-related gynaecological and urogynaecological complications when taking a medical history from their female patients.

### 4.2.1 WHY SHOULD HEALTH-CARE PROVIDERS ACTIVELY ENQUIRE ABOUT THESE CONSEQUENCES OF FGM?

Girls and women who experience long-term gynaecological and/or urogynaecological health complications caused by FGM often live with the symptoms of these conditions for months or even years without seeking care. This happens for a number or reasons.

- Some women may not have access to specialized gynaecological or urogynaecological health care or may be ashamed to consult a professional about these symptoms (2).
- Other girls and women learn to live with these long-standing or recurring conditions without reporting them because they are unaware – or reluctant to acknowledge – that FGM has caused the medical problems they are experiencing (3).
- In addition, if they know that other female community members live with similar health conditions, girls and women may not consider it relevant to consult a health-care provider about their symptoms.

For more guidance on how to raise and discuss the subject of FGM with patients, see Chapter 2.  $\bigcirc$  2



### 4.2.2 TAKING A HISTORY

Keep in mind that girls and women living with FGM often do not seek care for gynaecological or urogynaecological symptoms until they are advanced or cannot be hidden. If or when they do seek care, they may mention symptoms that are not directly related to the genitourinary system.

Greet the girl or woman and introduce yourself.



Ask your patient about her presenting complaint. Gain as much information as possible about the complaint.

If you suspect that your patient's health condition is due to FGM, ask her tactfully about any procedures she has had, including FGM. Use terminology that is familiar to her.

Ask her if she would like to share any information about her health and any problems she may have due to FGM.

**Directly enquire** about possible FGM-related gynaecological and urogynaecological complications (see section 4.1).  $\rightarrow$  4.1

### Reassure...

**Reassure** her that you are comfortable dealing with her condition and that her FGM status is not a barrier and will not prevent her from accessing health services.

### Listen...

Let the girl or woman express her feelings and give you the information she wants to share. If she starts crying, **be patient** and give support.

**Listen** carefully and empathize with her. Show concern to the patient and let her know you can help her.

Once it has been established that the girl or woman has undergone any type of FGM, this information and the subsequent clinical examination should be handled with professionalism and discretion.



The information (the type of FGM and the complications) should be recorded as required by the policy of the health-care institution.

**REMEMBER:** Pay attention to the following aspects when taking a medical history from a female patient.

- Make the girl or woman feel welcome and let her know that as a health-care provider your role is to provide support and care.
- Explain that all the questions you ask her are intended to help you reach a diagnosis and identify the best treatment options.
- Let her know that you will discuss all treatment options with her in detail so she can reach an informed decision about her care plan.
- Remind her that everything you discuss is confidential.



## 4.2.3 PERFORMING A CLINICAL EXAMINATION (2)



**Ensure** privacy and confidentiality.

**Explain** to the girl or woman that you will examine her and that this will include a genital examination.



Wash your hands thoroughly and put on gloves.

Expose and inspect the external genitalia.

5

6

4.2

In some places, consent from the husband or partner may be necessary before examining a woman's genitalia. In the case of minors, you must first obtain consent from her parents/legal guardians Manage... 📕 Follow management procedures as described for each condition (see sections 4.3–4.10). → 4.3 – 4.10 Take off the gloves and wash your hands. Assist and discuss... 10 After completing the procedure, **thank** the girl or woman for her cooperation. **Help** the patient to a sitting position, (11 assist her with dressing, if appropriate, and seat her comfortably for the next step of the procedure. **Share** your findings with the patient. Record... Record your findings.

# 4.3 CHRONIC VULVAR PAIN

The clitoris and surrounding genital tissues are highly innervated and therefore very sensitive. When FGM is performed, the clitoral glans and surrounding genital tissues, such as the clitoral prepuce and labia minora, are injured through cutting, pricking, nicking or stitching. This usually leads to the formation of inelastic scar tissue or, in some women, to the formation of keloids, cysts and neuromas. This causes some women to experience pain in the vulvar area that can become chronic. Pain in the vulvar area often manifests during sexual intercourse; however, it may also arise during daily activities (4). In addition, studies have shown that mental health disorders including anxiety, depression and posttraumatic stress – all conditions that can be caused by or related to FGM – may also be linked to the development of pain in the vulvar area (5).

### 4.3

#### HOW SHOULD IT BE MANAGED?

The management of chronic vulvar pain is as follows.

Try to **establish the cause** of the pain by taking a medical history and performing a genital examination.

**Obtain the woman's permission** before performing a genital examination.

- Inspect the vulvar area carefully.
- If the physical examination does not reveal any specific or detectable cause, potential psychosocial factors associated with the symptoms should be considered. Discuss this with your patient by asking her if she has any concerns regarding, for example, her fertility, marriage or partnership.

For more information on how to address psychological and sexual health complications of FGM, see Chapters 7 and 8.  $\bigcirc$  7  $\bigcirc$  8

#### **NOTE OF REFERRAL:**

• If the pain is severe or persists, refer the woman to a gynaecologist for further investigation and management.

 If the woman has type III FGM, inform and counsel her in detail about the need for deinfibulation, seek her informed consent and, if she agrees, make a referral or appointment for the procedure. Further details on deinfibulation and related counselling can be found in Chapter 6. →6

### MANAGEMENT OF 4.4 CLITORAL NEUROMA

A neuroma is a benign tumour that arises after the section or injury of a nerve. In the case of a clitoral neuroma, the dorsal clitoral nerve is injured during the cutting of the external portion of the clitoris – the clitoral glans (6). When the nerve fibres regenerate, they do so in a disorganized manner, which leads to the appearance of a clitoral neuroma (7).

A clitoral neuroma can be asymptomatic or it may cause allodynia (pain resulting from a stimulus – such as a light touch of the skin – which would not normally cause pain), sensations of electric discharge, or chronic pain in the surrounding area. With this condition, sitting, sexual intercourse, or even the friction of underpants, can cause pain. If the neuroma is symptomatic it should be managed.

#### HOW SHOULD IT BE MANAGED?

The management of a symptomatic clitoral neuroma is as follows (6).

- **Collect a detailed medical history** probing for typical symptoms such as chronic pain, allodynia and sensations of electric discharge in the genital area.
- Before touching the genital area, **explain** carefully what you will do and tell the woman she can ask you to stop the examination if it becomes too painful.

Perform a genital examination.

**Inspect** the vulvar area carefully; a neuroma is not always immediately visible. Be very gentle when examining your patient. A clitoral neuroma can be very painful!

You can check for the presence of a neuroma by **carefully touching** the area around the clitoral scar with a delicate object such as a cotton bud/swab, searching for painful or allodynic areas.

You can **offer lidocaine cream**, which the woman can apply to the painful area.

Advise the woman to wear loose underpants to avoid friction.

**NOTE OF REFERRAL:** *If the symptoms are severe, refer the woman for surgical excision of the neuroma.* 

4.4

# 4.5 REPRODUCTIVE TRACT INFECTIONS

Women who have undergone FGM have an increased risk of reproductive tract infections (RTIs), including bacterial vaginosis (8,9). Partial occlusion of the vaginal opening – due to the presence of scar tissue or infibulation, among women living with type III FGM – is a contributing factor for the development of these conditions. RTIs can be painful and may be accompanied by abnormal vaginal discharge. They can be recurrent and, if left untreated, may become persistent and lead to pelvic inflammatory disease (PID).

### HOW SHOULD THEY BE MANAGED?

The consequences of RTIs for reproductive health can be severe and life threatening. They include PID, infertility, ectopic pregnancy and adverse pregnancy outcomes, such as miscarriage, stillbirth, preterm birth and congenital infection (10).

The management of RTIs is as follows.

- 1 Take a medical history and perform a genital examination. Assess the woman to identify the type of FGM she has and the likely cause of the problem.
  - If laboratory facilities or rapid diagnostic tests (RDTs) are available, take a vaginal swab, and a cervical swab also, if appropriate, to test for the presence of infection and then provide treatment based on etiology.

In the absence of these facilities, treat the woman based on symptoms and signs (syndromic treatment) and according to national guidelines.

If an a sexually transmitted infection (STI) is diagnosed or suspected, provide partner management – ask the woman to notify her husband/partner and provide the same treatment for him.

If bacterial vaginosis or candidiasis are suspected, there is no need to treat the husband/partner.





# 4.6 MENSTRUAL DIFFICULTIES

Menstrual difficulties include dysmenorrhoea (painful menstruation), difficulty in passing menstrual blood, and haematocolpos and haematometra (accumulation of blood within the vagina and uterus, respectively). Girls and women who have undergone FGM often report dysmenorrhoea with or without menstrual irregularity. Possible causes include tight infibulation or severe scarring leading to narrowing of the vaginal opening. A very narrow vaginal opening may not allow normal menstrual flow, which can result in dysmenorrhoea and haematocolpos/haematometra.

### 4.6

#### HOW SHOULD THEY BE MANAGED?

The management of menstrual difficulties is as follows.

Try to **establish the cause** of the menstrual disorder by taking a medical history and performing a clinical examination.

If available, perform a pelvic ultrasound to confirm the cause.

On clinical examination, a palpable suprapubic mass may indicate haematocolpos.

#### **NOTE OF REFERRAL:**

- If the condition is severe, refer to a gynaecologist for further investigation and management.
- If the woman has type III FGM (infibulation) or a tight vaginal opening, inform and counsel her in detail about the need for deinfibulation or surgical removal of the scar tissue that will allow for normal menstrual flow. Seek her informed consent and, if she agrees, make a referral or appointment for the procedure. Further details on deinfibulation and related counselling can be found in Chapter 6. → 6

#### **IMPORTANT!**



Dysmenorrhea may be associated with conditions other than FGM; this should be investigated, and these conditions should be treated according to local protocol or national guidelines (e.g. endometriosis, adenomiosis).

# 4.7 URINARY TRACT INFECTIONS

Girls and women who have undergone FGM, especially among those who have type III FGM, have an increased risk of developing urinary tract infections (UTIs), including recurrent UTIs (9). UTIs in women living with FGM usually occur due to obstruction and stasis of the urine. This may happen among infibulated women or due to injury to the urethral opening. The obstruction affects the normal flow of urine, which is only able to slowly drip out when the woman urinates. This causes the urine to stagnate, making it susceptible to bacterial growth that can lead to a UTI, which can become recurrent.
# HOW SHOULD THEY BE MANAGED?

The management of UTIs is as follows.

1 Try to **establish the cause** of the UTI by taking a medical history and performing a genital examination **(obtain the woman's permission before performing a genital examination).** 

- **Ask** the woman if she has had similar symptoms or a confirmed UTI in the past year.
- **Inspect** the vulvar area carefully to establish the cause of infection.

**If laboratory facilities are available, send a urine sample** for urinalysis before providing treatment.

Give **antibiotic treatment** according to local protocol or national guidelines, whether or not laboratory facilities are available.

Advise the woman to drink plenty of water.

Advise her to return for care if the symptoms do not improve, get worse or return after treatment.



**Recurrent UTI:** A recurrent UTI is a symptomatic infection of the urinary tract (bladder and kidneys) that follows the resolution of a previous UTI, generally after treatment. Definitions of recurrent UTI vary and include two UTIs within the previous six months, or a history of one or more UTIs before or during pregnancy (15).

#### **NOTE OF REFERRAL:**

- If the woman experiences recurrent UTIs, refer her to a secondary care facility.
- If you identify damage to the urethral opening, you must refer the woman for surgical correction after providing treatment for the UTI.
- If infibulation (type III FGM) is the cause, inform and counsel the woman in detail about the need for deinfibulation. Explain to her that unless she is deinfibulated, the UTI is likely to recur and may eventually affect the bladder and kidneys. Seek her informed consent for deinfibulation and, if she agrees, make a referral or appointment for the procedure (see Chapter 6). → 6



#### WHO RECOMMENDATION

Deinfibulation is recommended for preventing and treating urologic complications – specifically recurrent urinary tract infections and urinary retention – in girls and women living with Type III FGM (1).

# 4.8 PAINFUL OR DIFFICULT URINATION

Painful or difficult urination may be caused by a UTI, or by difficulty passing urine due to damage to or partial obstruction of the urethral opening. In women living with FGM, scar tissue is usually the cause of the obstruction, and among women who have undergone type III FGM, the infibulated labia obstruct the normal passage of urine. Obstruction makes emptying the bladder difficult; urine can only exit drop by drop and will frequently continue leaking after urination has stopped. Women may also feel they are not able to empty their bladders completely.

### HOW SHOULD IT BE MANAGED?

The management of painful or difficult urination is as follows.

- Try to **establish the cause** of painful or difficult urination by first taking a medical history. Ask the woman how she urinates. The following questions can help you determine if your patient has a partial obstruction. - How long does it take you to empty your bladder? - Do you pass urine drop by drop? - Do you sometimes feel you cannot empty your bladder completely? - Do you lose drops of urine regularly during daily activities? Next perform a genital examination (obtain the woman's **permission first).** Inspect the vulvar area carefully to establish the cause of infection. If the pain is caused by a UTI, manage as indicated in section 4.7. - 4.7 **NOTE OF REFERRAL:** • If you identify damage to the urethral opening, you must refer the woman for surgical correction. • *If infibulation (type III FGM) is the cause, inform and counsel* 
  - the woman in detail about the need for deinfibulation, seek her informed consent and make a referral or appointment for the procedure (see Chapter 6).  $\rightarrow 6$

# 4.9 EPIDERMAL INCLUSION CYSTS IN THE GENITAL AREA

The cutting of the genital area leads to a wound. When a wound heals, it leaves a scar. Sometimes, external layers of the skin (epidermis) become "trapped" in deeper layers (dermis). This can lead to epidermal inclusion cysts that can gradually increase in size. These cysts can sometimes become inflamed or infected, resulting in pain and tenderness (16).

## HOW SHOULD THEY BE MANAGED?

If located in the genital area, epidermal inclusion cysts can cause discomfort during sexual intercourse and possible obstruction of the vaginal opening during childbirth. Some women may also feel unhappy with the appearance of the epidermal inclusion cyst.

The management of epidermal inclusion cysts is as follows.



**Inspect** the woman's genitalia to assess the size and location of the cyst.

**If you suspect a vulvar abscess** (localized collection of pus that usually appears as a tender and reddened mass, often painful and warm to touch), **manage** as indicated in Chapter 5, section 5.3.4.

If the cyst does not represent a potential obstruction or cause other difficulties, such as tenderness or pain during sexual intercourse, explain to your patient that it can be left undisturbed.



**NOTE OF REFERRAL:** If there is an epidermal inclusion cyst that is large, recurrently inflamed or located in an area that may cause obstruction during childbirth, the woman should be referred to have it removed under anaesthesia.

# 4.10 KELOIDS IN THE GENITAL AREA

Keloids are raised scars that grow excessively and can become larger than the original area of skin damage. Once it appears, a keloid can enlarge slowly for months or years and it may feel painful or itchy. Keloids can be difficult to treat. Even after surgical removal, a keloid scar may grow back in the same place.



### HOW SHOULD THEY BE MANAGED?

The management of keloids is as follows.

1 Take a medical history and perform a genital examination.

**Inspect** the woman's genitalia to assess the size and location of the keloid.

If the keloid does not represent a potential obstruction or cause other difficulties, such as tenderness or pain during sexual intercourse, explain to your patient that it can be left undisturbed.

#### NOTE OF REFERRAL:

- If there is a keloid that may cause obstruction or which causes other difficulties, the woman should be referred to a specialist experienced in removing keloid scars.
- If the presence or appearance of a keloid causes a woman excessive stress, consider referring her for surgery for psychological reasons.

#### **IMPORTANT!**

 $\rightarrow$ 

Some women may experience changes in their sexual function after the removal of cysts or keloids that were in close contact with the clitoral glans or remnant (17).

# 4.11 FAMILY PLANNING FOR WOMEN LIVING WITH FGM

Family planning is as appropriate for women living with FGM as it is for any other woman. The medical eligibility criteria set by WHO can be used to determine the most suitable contraceptive methods for these women (18).

# CONSIDERATIONS WHEN HELPING YOUR PATIENT CHOOSE SUITABLE CONTRACEPTION

- It is important that a genital examination be carried out to identify the type of FGM and to check that there are no problems that need attention, especially infections.
- Women who have been infibulated may have difficulties in using a method which has to be inserted vaginally, such as female condoms, a diaphragm, a cervical cap or an intrauterine device (IUD). They may also have difficulty with male condoms.
- Since women with FGM of any type are prone to RTIs, IUDs should be used only after careful consideration *(19)*.

#### **ADDITIONAL RESOURCES**

Detailed information and guidance on contraceptive methods can be found in the WHO publication *Medical eligibility criteria for contraceptive use, fifth edition (18).* 



# 4.12 CERVICAL SCREENING FOR WOMEN LIVING WITH FGM

Like any other woman, women who have undergone FGM may have been exposed to the human papillomavirus (HPV) and therefore are also at risk of developing cervical cancer. As such, women living with FGM should also undergo cervical screening at regular intervals.



**HPV:** The human papillomavirus (HPV) is the most common viral infection of the reproductive tract – most people get it at some time in their life. Cervical cancer is caused by certain types of HPV that are passed through sexual contact (20).

# 4.12

# DISCUSSING CERVICAL CANCER SCREENING WITH YOUR PATIENT

Taking a cervical sample for screening can sometimes be difficult if the woman has undergone type III FGM or has extensive genital scarring. In addition, some women may not know about the need for or the purpose of cervical screening and will require a careful explanation of the procedure before they agree to it. The following considerations may help you explain the importance of cervical screening to your female patient.

- Use clear and straightforward simple language to explain the purpose and the importance of cervical screening. Arrange for a female interpreter if needed.
- Tell the woman that the cervix is the entrance to the uterus from the vagina and that the cervical screening test is a method of detecting abnormal cells on the cervix. Tell her that detecting and removing any such abnormal cervical cells can prevent cervical cancer.
- Invite the woman to ask questions.

Record all relevant clinical information in the patient's medical record.

**NOTE OF REFERRAL:** *Refer her for cervical screening.* 

**IMPORTANT!** Cervical screening can be a little uncomfortable but it is not a risky procedure and it should not be painful

# RECOMMENDATIONS FOR HEALTH-CARE PROFESSIONALS PERFORMING CERVICAL SCREENING



Always introduce yourself to your patient and explain what you are about to do.

Ask the woman if she has had cervical screening before. For example, you can ask her:

Have you had cervical screening or a Pap test before?

Have you ever had an uncomfortable cervical screening or Pap test experience in the past? If so, can you tell me why this was difficult for you?



It may sometimes be difficult or impossible to insert the speculum in women who have undergone FGM.

Explain to her that you will need to perform a genital examination to decide if you can do the test, and obtain her permission to perform this examination.



Assess the vaginal opening and the level of difficulty for performing cervical screening.



**IMPORTANT!** All women should be screened for cervical cancer at least once between the ages of 30 and 49 years, or in accordance with national guidelines (19). Ø

Conduct the cervical screening if possible, but reassure her that the procedure can be stopped if it becomes too painful.

- If speculum insertion is possible, use the smallest available size.
- Applying lubrication on the speculum edges can be helpful.
- Instruct the woman to use relaxation techniques, such as deep breathing.



Difficulties performing the screening may highlight the need for deinfibulation. When you have completed the screening, discuss deinfibulation with the woman, and her husband/partner where appropriate.



If cervical screening is not possible, do not insist. Explain to the woman why the test was not possible and discuss management options, such as performing deinfibulation if she has type III FGM.

#### ADDITIONAL RESOURCES

Detailed information and guidance on cervical screening can be found in the WHO publication *Comprehensive cervical cancer control: a guide to essential practice (20).* 



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CARING FOR WOMEN WITH FGM DURING PREGNANCY, LABOUR, CHILDBIRTH & POSTPARTUM

# After reading this chapter you should be able to:

- Understand the reasons for the obstetric risks associated with FGM
- Develop an adequate birth plan in the context of FGM
- Manage common complications which may occur during pregnancy as a result of FGM
- Use proper history-taking and physical examination skills to:
  - assess FGM status (FGM versus no FGM)
  - assess the type of FGM (I, II, III or IV)
  - identify and prevent complications that may occur during labour, childbirth and the postpartum period, which may be related to FGM
- Understand how to manage labour and childbirth in women with FGM
- Understand the particular considerations of managing women with type III FGM during pregnancy, labour, childbirth and the postpartum period
- Understand how to determine whether episiotomy is required and when to perform the procedure
- Understand how to monitor the postpartum period, including complications from childbirth

## In this chapter



#### 5.1 OBSTETRIC RISKS ASSOCIATED WITH FGM



# 5.1 OBSTETRIC RISKS ASSOCIATED WITH FGM

Many women who have undergone FGM experience a healthy pregnancy and childbirth. However, evidence shows that FGM is associated with a number of obstetric complications, and that greater risk is associated with the most severe forms of FGM (i.e. those classed as type III FGM, also referred to as "infibulation") (1,2).

# **5.1.1 INCREASED OBSTETRIC RISKS FACED** BY WOMEN WITH FGM AND THEIR BABIES

Women who have undergone FGM have an increased risk of (1,2,3):

- caesarean section
- postpartum haemorrhage (PPH)
- episiotomy
- prolonged or difficult labour
- obstetric tears and lacerations
- instrumental childbirth
- extended maternal hospital stay.

Babies born to women who have undergone FGM have an increased risk of:

- stillbirth and early neonatal death
- asphyxia and resuscitation of the baby at birth.

# 5.1.2 WHY DO WOMEN WHO HAVE UNDERGONE FGM HAVE AN INCREASED RISK OF OBSTETRIC COMPLICATIONS?

Although several obstetric complications associated with FGM may also occur among women who have not undergone the procedure, women who are living with FGM often have specific conditions that increase the risk of developing complications during pregnancy and childbirth. The following are some of these conditions (4).

#### TIGHT VAGINAL OPENING

#### Why does this happen?

All forms of FGM can result in scarring of the vulvar area, which may tighten or obstruct the vaginal opening. Scarring can be particularly severe in women who have undergone type III FGM. In some cases, infection and inflammation at the time FGM was performed can result in vulvar adhesions, which also may tighten or obstruct the vaginal opening.

### What are the consequences?

Proper management of labour requires a sequential assessment of the woman's cervical dilation, and of the presentation, position and descent of the baby. A tight vaginal opening makes it difficult for the health-care provider to perform vaginal examinations to properly assess the progress of labour, and for the woman such examinations can be uncomfortable and painful. Without the ability to assess progress, non-progressive labour cannot be adequately identified or managed. During pregnancy, the management of situations such as antepartum vaginal bleeding and incomplete abortion is also affected by the lack of the ability to do vaginal examinations.

# RECURRENT REPRODUCTIVE AND URINARY TRACT INFECTIONS (RTIS AND UTIS)

### Why does this happen?

Women living with FGM have an increased risk of reproductive and urinary tract infections (5,6). Conditions that lead to the tightening or obstruction of the vaginal opening, such as the presence of scar tissue, vaginal adhesions or infibulation among women living with type III FGM, are contributing factors that can lead to recurrent RTIs and UTIs in women living with FGM.

### What are the consequences?

RTIs and UTIs can interfere with the normal progress of pregnancy and sometimes lead to preterm labour and childbirth.

#### EPIDERMOID INCLUSION CYSTS AND KELOIDS

### Why does this happen?

The cutting of the genital area can sometimes lead to external layers of the skin (epidermis) being "trapped" in deeper layers (dermis). This can lead to epidermoid inclusion cysts. Keloids occur from the overgrowth of scar tissue.

### What are the consequences?

These conditions may cause discomfort for the woman and potential obstruction of the vaginal opening during childbirth.

# **5.2 ANTENATAL CARE**

Antenatal care, the care a woman receives during pregnancy, is a critical opportunity for health-care providers to assess women and to deliver care, support and information (7). In the case of women living with FGM this is a particularly important opportunity.

# 5.2.1 CONSIDERATIONS WHEN DEVELOPING A BIRTH PLAN

Antenatal care visits may be the only occasions on which many women engage with the health system, and therefore these visits present an ideal opportunity to provide assessment, support and appropriate care to women who have experienced FGM. This includes identifying whether or not she has undergone FGM and what type; treating common health complications of FGM that may arise during pregnancy; discussing the potential for complications to arise during labour and childbirth and creating an appropriate birth plan; and promoting prevention messages for the next generation.

It is also an important opportunity to build rapport and a trusting relationship with the woman so that you can better understand her needs and ensure positive communication (7) (see further information on communicating with patients about FGM in Chapter 2).

**REMEMBER:** All pregnant women should receive adequate and timely antenatal care that respects their dignity (7). A birth plan will allow both the provider and the woman to plan in advance for childbirth and will ensure the healthiest possible outcome for the woman and the baby.

#### WHAT SHOULD I ASSESS WHEN DEVELOPING A BIRTH PLAN?

Pregnant women from communities where FGM is traditionally performed should receive routine antenatal care that incorporates additional assessment of the following questions.



#### Has the woman undergone FGM (or What is her FGM status?)

- What type of FGM has she undergone?
- 3

What health conditions does the woman have and are they potentially related to FGM?

You can assess these aspects by taking a clinical history and by performing a vaginal examination (see sections 5.2.2 and 5.2.3).

**IMPORTANT!** 

A birth plan must be adapted to each individual woman. In the case of women living with FGM, to develop an adequate birth plan it is critical that you assess the type of FGM she has.

### ALSO PROVIDE INFORMATION YOU WOULD PROVIDE TO ANY PREGNANT WOMAN

Don't forget that in addition to any special care the woman may need because of her FGM status, during antenatal care visits you should also provide the same information you would provide to any pregnant woman:

- basic health during pregnancy;
- the importance of healthy eating and keeping physically active during pregnancy;
- daily oral iron and folic acid supplementation and other contextspecific dietary supplements;
- the health risks of tobacco use (past and present) and exposure to second-hand smoke;
- sexual health during pregnancy;
- childbirth and postpartum care (including breastfeeding);
- contraceptive alternatives after childbirth;
- where to access further psychological or social support, if needed (7).

### ADDITIONAL RESOURCES

• You will find detailed information on antenatal care in *WHO recommendations on antenatal care for a positive pregnancy experience (7).* 





### **5.2.2 TAKING A CLINICAL HISTORY** DURING PREGNANCY

Women who have undergone FGM may sometimes feel anxious when visiting an antenatal care clinic. For example, they may be fearful of being seen by a health worker who is unfamiliar with FGM who may therefore recommend inappropriate interventions. This can make the communication between the woman and her health-care provider challenging, which in turn may cause the woman more anxiety. Following are suggestions for taking a good clinical history during pregnancy.



#### Do not immediately ask the woman about her FGM status.

It is best to start by taking a full history that includes asking general questions about her physical and mental health as you would do for every pregnant woman presenting for antenatal care. This will allow her to feel more at ease.

A good time to ask about FGM is when you ask about her surgical or reproductive history. At this time, questions like this could help you to raise the subject:

*I know many women from your country have experienced some form of genital cutting. Do you know if this was done to you?* 

Make the woman feel welcomed and respected, and respect her privacy and confidentiality at all times.

# What other questions should I ask a pregnant woman who has undergone FGM?



vaginal discharge, to rule out the possibility of an ongoing reproductive tract infection (RTI);

urinary symptoms, such as how long it takes the woman to empty her bladder and whether this causes pain, to rule out the possibility of partial urinary tract obstruction or infection;

previous complications during pregnancy and childbirth, such as prolonged or obstructed labour, postpartum haemorrhage (PPH) or resuscitation of her newborn at birth;

worries or fears associated with the pregnancy or chilbirth, including nightmares or flashbacks regarding her genital cutting;

past experience of deinfibulation and/or re-infibulation;

whether she has any specific questions she would like to ask.



## 5.2.3 PERFORMING A GENITAL EXAMINATION DURING PREGNANCY

If the woman reveals that she has undergone FGM or if she is not sure, make sure she understands the importance of a genital examination that will allow you to check for the presence of specific conditions that are likely to interfere with future genital examinations or treatment, or cause problems during labour and childbirth. Following are suggestions for performing a genital examination during an antenatal care visit.

#### **BEFORE YOU START THE GENITAL EXAMINATION**





Make sure the woman feels comfortable and understands that you will perform a genital examination.



**Explain** to her how and why a genital examination is performed. Ask her if she has any questions.

If available, **offer** her a clean sheet or cloth that she can wrap around her waist before lying on the examination table.

#### **DURING THE GENITAL EXAMINATION:**

Identify FGM type...

If possible, **identify** the type of FGM she has undergone, if any.

Look for...

**Look for conditions** that are likely to interfere with future vaginal examinations, or cause problems during pregnancy and childbirth.

- infibulation (type III FGM);
- a tight vaginal opening, scar tissue or vaginal adhesions;
- signs of RTIs, such as abnormal vaginal discharge;
- abscesses;
- epidermoid inclusion cysts and keloids.

#### AFTER THE GENITAL EXAMINATION:

Discuss...

**Share the information** learnt from the examination with the woman and discuss a birth plan with her – and with her husband/partner, if appropriate.

# Record...

8 For the purposes of developing a birth plan, it is very important that you clearly **record** in the woman's patient record the type of FGM she has. See section 5.2.4 for examples of such drawings.

#### **IMPORTANT!**

Even after a detailed physical examination sometimes it is not possible to correctly identify exactly the type of FGM she has. Including a simple drawing of the vulvar area that clearly describes the main anatomical structures and which ones have been removed or damaged can be very useful. See section 5.2.4 for examples of such drawings.

## 5.2.4 VISUAL RECORDING OF FGM

The identification and recording of FGM can sometimes be challenging, especially when a girl's or woman's genital cutting does not look exactly the same as that described in the WHO typology (see Chapter 1, section 1.3).  $\rightarrow$  13

If after performing a genital examination you cannot determine exactly the type of FGM your patient has, you should at least record that she has undergone FGM (i.e. her genitalia are not unaltered as shown in Figure 5.1) and describe which anatomical structures have been removed or damaged. Take the following steps.

- Start by making a simple drawing of the female genitalia in your patient's medical record (see Figure 5.2).
- Based on the findings of the genital examination, specify which anatomical structures were removed or altered by marking these with a pen or pencil (see the red markings in Figures 5.3, 5.4, 5.5 and 5.6).
- 3 It is also recommended that you describe the highlighted anatomical structures by labelling them (e.g. "clitoral glans" or "labia minora") or adding in a few words about what your drawing shows (i.e. "prepuce and clitoral glans removed" or "labia majora closed").

Figures 5.1–5.6 are examples of hand-made drawings that depict some types of FGM. Keep in mind that some girls or women may have different forms of FGM and therefore you should always develop your own drawings to put in the patient's medical record based on the findings of the genital examination. All structures affected should be noted.



Figure 5.1 Diagram of unaltered genitalia



*Figure 5.3* Type I: prepuce and clitoral glans removed



Figure 5.5 Type IIIa: labia minora closed



Figure 5.2 Drawing of unaltered genitalia



*Figure 5.4* Type II: prepuce, clitoral glans and labia majora removed



Figure 5.6 Type IIIb: labia majora closed

# MANAGEMENT OF 5.3 PREGNANCY-RELATED COMPLICATIONS ASSOCIATED WITH FGM

There are a number of health complications associated with FGM that should be identified and managed if they appear during pregnancy.
## PREGNANCY-RELATED COMPLICATIONS ASSOCIATED WITH FGM

These include (4):

- Reproductive tract infections (RTIs)
- Vulvar adhesions
- Urinary tract infections (UTIs)
- Vulvar abscesses
- Epidermal inclusion cysts and keloids
- Mental health problems (see Chapter 7).

#### **IMPORTANT!**



The guidance provided in this chapter should complement existing WHO guidelines on the management of specific pregnancy-related complications (15).

## **5.3.1 REPRODUCTIVE TRACT INFECTIONS**

Reproductive tract infections (RTIs), including some sexually transmitted infections (STIs), can often be asymptomatic, therefore it is important that you ask about RTI/STI signs and symptoms at each antenatal visit or if you perform a vaginal examination on a patient for other reasons (whether during pregnancy or not).

Symptoms suggestive of infection include abnormal vaginal discharge, vulvar itching, lower abdominal pain, pain on urination, spotting after sexual intercourse, and fever (8).

**If laboratory facilities or rapid diagnostic tests (RDTs) are available, take a vaginal swab**, and a cervical swab also, if appropriate, to test for the presence of infection and then provide treatment based on etiology.

In the absence of laboratory testing facilities or RDTs, treat the woman based on symptoms and signs (syndromic treatment) and according to national guidelines.

If an STI is diagnosed or suspected, provide partner management – ask the woman to notify her husband/ partner and provide the same treatment for him.

If bacterial vaginosis or candidiasis is suspected, there is no need to treat the husband/partner. **Provide guidance** about vulvar hygiene (see the box below on "Discussing correct vulvar hygiene").

**NOTE ON FOLLOW-UP:** Advise the woman that if the symptoms continue she should return for care.

### DISCUSSING CORRECT VULVAR HYGIENE (4,9,10)

- Use only clean water, or mild soap and clean water.
- Avoid all perfumed products or "washes".
- Only wash yourself "outside"; there is no need to clean yourself "inside" (do not use vaginal douches).
- If you prefer to use a cleanser, use an unscented, soap-free skin cleanser or soap once a day. Make sure you rinse thoroughly.
- Wipe yourself from front to back.
- Always dry your vulva thoroughly after washing your genital area.

#### ADDITIONAL RESOURCES

Detailed information on RTI and STI assessment and management, including simple flowcharts to guide health-care providers in using the syndromic approach, is available in the WHO publication *Sexually transmitted and other reproductive tract infections: a guide to essential practice (8)*.



• Up-to-date WHO guidelines for STI treatment are also available for chlamydia, gonorrhoea, syphilis and herpes (11–14).









## 5.3.2 VULVAR ADHESIONS

Vulvar adhesions appear due to inflammation or infection that may have occurred at the time that FGM was performed. They appear as thin, filmy tissue that partially covers the vaginal opening.

#### Put on sterile gloves.

If the adhesions are thin, under local anaesthesia, perform blunt separation of the adhesions by gently pulling the labia laterally with the fingers or cotton-tipped swabs. 0

Thicker adhesions may require surgical separation under local anaesthesia.

**Provide guidance** on vulvar hygiene (see the box on "Discussing correct vulvar hygiene" in section 5.3.1).

**NOTE ON FOLLOW-UP:** *Give the woman a follow-up appointment in order to monitor progress.* 



## 5.3.3 URINARY TRACT INFECTIONS

Urinary tract infections (UTIs) are common in pregnant women and they have been associated with adverse pregnancy outcomes, including preterm birth and small-for-gestational-age newborns (7).

**Symptoms** include dysuria (pain and discomfort during urination), increased urinary urgency and frequency, strong-smelling urine, haematuria (urine that appears red or pink due to the presence of blood) and pelvic pain.

If laboratory facilities are available, send a urine sample for urinalysis before providing treatment.

Give **antibiotic treatment** according to local protocol (i.e. national guidelines or hospital protocol), whether or not laboratory facilities are available.

**NOTE ON FOLLOW-UP:** Advise the woman that if the symptoms continue she should return for care.

## 5.3.4 VULVAR ABSCESS

A vulvar abscess is a localized collection of pus that usually appears as a tender and reddened mass in the genital area. It is often painful and warm to touch.

To relieve the pain and promote spontaneous drainage of the abscess, **recommend soaking the affected area** for 10–15 minutes in clean warm water (e.g. in the bathtub) several times a day for three or four days, if possible. You can also recommend holding a warm compress (cotton or a flannel soaked with hot water) against the affected area.

**NOTE OF REFERRAL:** If the abscess does not drain spontaneously, perform or refer for surgical drainage.

**Provide guidance** on vulvar hygiene (see the box on "Discussing correct vulvar hygiene" in section 5.3.1).

**NOTE ON FOLLOW-UP:** *Give the woman a follow-up appointment in order to monitor progress.* 

## 5.3.5 EPIDERMAL INCLUSION CYSTS AND KELOIDS

Epidermal inclusion cysts appear as small, hard lumps that develop under the skin, including in the genital area. They grow slowly and are usually not painful and can often go untreated. Treatment may be necessary if the cyst becomes infected or if, due to its size, it obstructs the vaginal opening. Keloids are raised scars that grow excessively and can become larger than the original area of skin damage.

Assess the size and location of the cyst or keloid.

**NOTE OF REFERRAL:** If it is big or located in an area that may cause obstruction during labour, make a referral for the woman to give birth in a hospital where there are facilities for caesarean section, in case this is required for childbirth (4).

# 5.3.6 IF THERE ARE NO OBSERVED OR REPORTED COMPLICATIONS

Where type I, II and IV FGM did not result in any observed or reported complications, you should take the following actions.

**Reassure** the woman that her FGM status is unlikely to cause complications during childbirth and invite her to ask any questions about her excision or any other issues relating to her pregnancy or reproductive and sexual health.

Discuss the agreed birth plan with her.

**Continue** antenatal care visits as per routine.

**NOTE ON FOLLOW UP:** *During follow-up visits, ask the woman if she needs any special support.* 

## ASSESSMENT OF 5.4 WOMEN WITH TYPE III FGM DURING PREGNANCY

Women who have been infibulated (type III FGM) are at increased risk of obstetric complications during childbirth due to the obstruction that covers the vaginal opening (2). These women may have variable degrees of closure and variable size of the vaginal opening. To develop an appropriate birth plan it is important that you adequately assess a woman with type III FGM from as early as possible during antenatal care – at the first visit if possible.

## ASSESSING WOMEN WITH TYPE III FGM DURING PREGNANCY

If during any antenatal visit the woman tells you for the first time – or you come to suspect – that she has undergone type III FGM, and this hasn't been previously documented in her patient record, then a routine genital examination will help you confirm this.

The objective of this antenatal genital examination, which should ideally be done during an early antenatal visit, is to confirm that she has undergone type III FGM and assess the size of her vaginal opening, and to detect any additional vulvar abnormalities or related health complications (i.e. epidermal inclusion cysts and keloids, vulvar abscesses or adhesions, RTIs or UTIs; see sections 5.1 and 5.3).  $\rightarrow$  51  $\rightarrow$  53

Make sure the woman understands the need for and agrees to undergo a genital examination.



### PERFORMING A GENITAL EXAMINATION OF WOMEN WITH TYPE III FGM DURING PREGNANCY

### Explain & reassure...

**Obtain the woman's permission** before performing a genital examination.

2 Before beginning, ask the woman if she has been pregnant before and, if so, about her experiences during childbirth, which may indicate whether she is likely to have problems this time.

Ask the woman to lie on her back on the examination table.

Look for...

Depending on the size of the vaginal opening, carefully assess the elasticity of the tissue with your index and middle fingers or a cotton swab/bud.

As a general rule, if the urinary meatus is visible (i.e. if there is no barrier from the urinary meatus downwards), major obstructive problems at childbirth are unlikely.

**REMEMBER:** It is not necessary to perform a vaginal examination (insertion of a speculum or fingers) to confirm infibulation, as this condition can be identified by visual inspection of the external genitalia.

## Discuss...

After completing the examination, **communicate** the results to the woman – this will help her understand why the examination was necessary, what was found, and why this information is useful.

#### **IMPORTANT!**

If your assessment shows that the woman has a tight vaginal opening due to her infibulation, you should discuss the need for deinfibulation with her, and with her husband/ partner at the earliest opportunity, if appropriate (see Chapter 6).  $\rightarrow$  6

## Record... 🗐

**Record** your findings! Making a visual record (drawing) of the appearance of the vulva may help to avoid unnecessary examinations for the woman in future. Section 5.2.4 includes examples of drawings you can use.  $\rightarrow$  5.2

## ASSESSMENT & MANAGEMENT OF 5.5 LABOUR & CHILDBIRTH

Women with type I, II and IV FGM without complications, and women who undergo deinfibulation during pregnancy, are all likely to have a childbirth that will require routine management.

However, women with an intact infibulation (type III FGM) and those who have extensive scarring of the external genitalia have a higher risk of encountering complications during childbirth, both for themselves and for their babies (see section 5.1).  $\Rightarrow$  (51)

## LABOUR & CHILDBIRTH

Women with type I, II and IV FGM without complications, and women who undergo deinfibulation during pregnancy, are all likely to have a childbirth that will require routine management.

However, women with an intact infibulation (type III FGM) and those who have extensive scarring of the external genitalia have a higher risk of encountering complications during childbirth, both for themselves and for their babies (see section 5.1).

#### WHO RECOMMENDATION

WHO recommends providing respectful maternity care – which refers to care organized for and provided to all women in a manner that maintains their dignity, privacy and confidentiality, ensures freedom from harm and mistreatment, and enables informed choice and continuous support during labour and childbirth. (16)



### 5.5.1 INITIAL ASSESSMENT OF WOMEN WITH FGM DURING LABOUR

Take a history of labour and perform a physical examination as you would for any woman in labour.



**Complete** the routine clinical **history-taking**.

Check if she has undergone FGM and what type (and/or assess if she has already had deinfibulation) by looking at her maternity record or case notes or, if this is not available, by asking her.

4

**If she has undergone FGM** and if she has had any previous pregnancies, **ask** her if she has had any complications due to FGM in previous pregnancies.

#### **IMPORTANT!**

If this is the first encounter (i.e. she has not attended any antenatal visits) and she has type III FGM, discuss at the earliest opportunity the need for deinfibulation before or at the time of childbirth.

## Examine...



**Explain** to the woman that you will perform a physical examination.

6

**Do a general assessment**, including vital signs such as blood pressure and body temperature.

**Perform** abdominal inspection, palpation including Leopold's manoeuvres, and fetal auscultation.

**Palpate the bladder** (also, ensure that the bladder is emptied regularly).

**Examine** the external genitalia with special care to assess the type of FGM. Assess in particular the tightness of the vaginal opening to evaluate whether it will allow for normal vaginal childbirth. The procedure for this assessment is described in Box 5.1.

10

If the results of the assessment indicate that the vaginal opening is normal or if it allows normal vaginal examination, then vaginal examination can be performed as usual.

If the vaginal opening is tight or the woman has type III FGM, end the examination and proceed to the next steps.

## Explain & reassure...

**Explain** the potential risks associated with having a tight vaginal opening during labour and childbirth (see section 5.1).

11 Inform her that there may be an increased risk of medio-lateral episiotomy during childbirth to expand the vaginal opening, and explain carefully what is involved. **Reassure** her that this will be performed only if necessary.

#### **IMPORTANT!**

Deinfibulation should always precede the performance of an episiotomy. This will help enlarge the vaginal opening, allowing the decision regarding episiotomy to occur as it would for any woman in labour.

12

If she has type III FGM, and antepartum deinfibulation was not performed and/or if she was not counselled about the procedure, explain that she will need to be deinfibulated and explain what is involved (see Chapter 6).

### BOX 5.1 Procedure for performing an assessment of the vaginal opening

- Explain to the woman what you are going to do and why such an assessment is needed.
- Ask for permission to examine her genitalia (ask each time an examination is required).
- Prepare the necessary equipment: a tray with antiseptic, sterile swabs and gloves.
- Ask the women to lie on her back; expose only the parts of the body that need to be accessed during the assessment.
- Wash hands with soap and water. Put on the gloves.
- Clean the external genitalia with an antiseptic swab.
- Instruct the woman to relax by taking a deep breath while you are introducing a finger into the vaginal opening.
- Try slowly and carefully to introduce first one finger into the vagina to measure the tightness of the vaginal opening. If it allows one finger, try to move the finger upward and downward, and left to right. If there is space for a second finger, try to widen the two fingers and check the resistance.
- Once the assessment is complete, cover her and share with her the information learnt from the exam.

### 5.5.2 MONITORING PROGRESS OF LABOUR

Management of women with FGM during labour is the same as for any other women, except in the case of infibulation (type III FGM), extensive scarring and/or a tight vaginal opening.

- **Observe** the woman closely and routinely monitor progression of labour and her vital signs.
- If necessary, labour can be assessed using other parameters such as contractions and descent of the baby. If needed, cervical dilation can be assessed through rectal evaluation.
  - **Record** all observations in the partogram.
  - **Give** the woman clear and simple **information** about what she should expect during childbirth.

#### **IMPORTANT!**

Monitoring the progress of labour may be difficult in women with FGM who have a tight vaginal opening due to scarring or type III FGM. In particular, vaginal examination may not be possible. 5 In the case of women with a tight vaginal opening, assess the vaginal opening carefully and regularly during labour to evaluate whether it will be able to stretch sufficiently during childbirth. The procedure to assess the vaginal opening is described in Box 5.1.

If during the assessment it is possible to introduce a finger but impossible to stretch the opening at all because of resistance due to scar tissue, inform the woman that it will be necessary to open up the vaginal opening during childbirth by performing a medio-lateral episiotomy.

If during the assessment it is impossible to introduce a finger, or even the tip of a finger, into the vagina, this means that the vaginal opening is extremely tight – equivalent to type III FGM. Inform the woman that deinfibulation is necessary, obtain her consent and perform the procedure as soon as possible. Instructions on how to perform deinfibulation are provided in Chapter 6.

#### **IMPORTANT!**

If intrapartum deinfibulation is required, the procedure can be performed during the first stage of labour or during childbirth. Deinfibulating during the first stage of labour will make it easier to monitor the progress of labour.

## 5.5.3 CHILDBIRTH

## TIGHT VAGINAL OPENING DUE TO EXTENSIVE SCARRING CAUSED BY FGM

If scarring due to FGM has caused a tight vaginal opening (as determined by assessment, described in Box 5.1), there may be a need to increase the vaginal opening by doing a medio-lateral episiotomy.

This is usually performed under local anaesthesia, at the height of a contraction during the second stage of labour, when the baby is crowning.

Usually a tight vaginal opening will have been identified during the physical examination at the time of the initial assessment of any woman with FGM in labour, which would usually be during the first stage of labour, and the woman should have been informed at that time about the need for an episiotomy.

However, if the woman has arrived at the ward already in the second stage of labour, assess the vaginal opening (see Box 5.1) and explain to her about the need to expand the opening by performing a medio-lateral episiotomy. Inform her of when and how this will be done.

This should not be performed before the baby's head is touching the perineum!

## TIGHT VAGINAL OPENING DUE TO TYPE III FGM (INFIBULATION)

Deinfibulation, if it has not been performed during pregnancy or during the first stage of labour, can be performed during childbirth.

At this stage, the deinfibulation incision should be made after the administration of a local anaesthetic (or epidural anaesthesia) and at the height of a contraction to minimize the possibility of pain.

The suturing of the cut can be delayed until after childbirth.

For detailed information on how to perform deinfibulation, refer to Chapter 6.  $\bigcirc$  6

## **REMEMBER:**

Deinfibulation should always precede the performance of an episiotomy.

Once the woman has been deinfibulated, it may be possible for her to give birth with the perineum intact. Episiotomy should only be carried out if the scarring due to FGM has caused extensive inelasticity of the skin around the vagina. As in other women during childbirth, episiotomy should not be performed routinely (15).

## 5.6 THE POSTPARTUM PERIOD IN WOMEN LIVING WITH FGM

The postpartum period – the days and weeks following childbirth – is a critical phase in the lives of women and newborn babies (17). Health-care providers must be aware that certain health complications related to FGM may also occur after childbirth.

## **5.6.1 FGM-RELATED HEALTH COMPLICATIONS** THAT MAY OCCUR AFTER CHILDBIRTH

Health-care providers should remain vigilant to the following conditons:

- *postpartum haemorrhage* from an atonic uterus, which is more common after prolonged labour;
- *excessive blood loss and injury to neighbouring structures*, such as the urethra and bladder anteriorly and the rectum posteriorly, due to extensive perineal tears;
- *urine retention* if the urethra has inadvertently been sutured during repair of tears;
- damage to neighbouring structures such as the urethra and bladder if an incision (episiotomy or deinfibulation) has been incorrectly performed;
- *infection of sutured perineal tears* that may lead to wound breakdown and, in severe cases, septicaemia;
- Extensive perineal tears and/or vesico-vaginal fistulae or rectovaginal fistulae – complications that a woman with type III FGM may have suffered if deinfibulation was not performed;
- *psychological problems* if childbirth has been difficult, especially if it resulted in the loss of her baby.

To detect these conditions, it is vital that the woman is properly assessed after childbirth.

# 5.6.2 IMMEDIATE ASSESSMENT OF THE WOMAN AFTER CHILDBIRTH

**Check** if the uterus has contracted by assessing the uterine tonus through abdominal palpation.

Keep your gloves sterile, change them as needed.

#### If the uterus has not contracted:

- start uterine massage;
- administer oxytocic drugs WHO recommends administering intravenous (IV) or intramuscular (IM) oxytocin (10 IU, IV/IM);
- **Examine** the vulvar area closely for tears, ensuring that the entire circumference of the vulva, including all surfaces of the labia majora and minora, have been examined. Rinse if necessary to improve visual inspection.
- Gently use a speculum and good light to **check for tears** in the vaginal wall and on the cervix, suturing any that are found.
- **Ensure** there is no bleeding from vaginal or cervical tears at the end of the procedure.

#### ADDITIONAL RESOURCES

For more information on how to manage postpartum haemorrhage, refer to WHO recommendations for the prevention and treatment of postpartum haemorrhage (18).





## 5.6.3 MANAGEMENT OF A WOMAN WITH FGM AFTER CHILDBIRTH

The management of women with FGM during the postpartum period is essentially the same as for any other women. However, women who have undergone deinfibulation during pregnancy, labour or childbirth may need additional care and psychological support during this period. The following steps are suggested.

- **Provide counselling and support** to help her adapt to the changes following deinfibulation, and to discourage her from seeking re-infibulation after leaving the health centre.
  - Advise her to wear loose underwear to reduce discomfort caused by friction.
  - If necessary, **provide counselling to the husband/partner** as well, to make him aware of the importance of not closing the opened-up infibulation, and to help him understand the changes that may arise during sexual intercourse.
  - **Remind** him that sexual intercourse should only be reinitiated once his wife/partner feels ready and the wound has had adequate time to heal, which typically occurs 4–6 weeks after the surgical procedure.
- Finally, take time to **reassure** the woman by reinforcing the reasons that the deinfibulation was performed, highlighting that this will improve her health. If needed, **explain** this to the woman's husband/partner and family.



## 5.6.4 POSTPARTUM FOLLOW-UP

- Like any other woman in the postpartum period, those who have undergone FGM should be advised about the importance of:
  - adequate nutrition;
  - personal hygiene, especially handwashing;
  - care of the newborn, including breastfeeding;
  - birth spacing and family planning (17).
- 2 Contraceptive options should be discussed, and contraceptive methods should be provided if requested. For more information on contraceptive options for women living with FGM, see Chapter 4.
- 3 All women should be encouraged to mobilize as soon as appropriate following childbirth. They should be encouraged to take gentle exercise and make time to rest during the postnatal period.
  - In malaria endemic areas, mothers and babies should sleep under insecticide-impregnated bednets.
- Assure the woman that you are available to answer any queries she might have about her own care or that of the baby, or concerns about sexual matters or psychological distress. Explain to her that she can come back to see you any time should additional concerns arise after discharge from the health centre.

## **REMEMBER:**

The postpartum period is an ideal opportunity to advocate for the prevention of FGM!

A woman with any type of FGM who delivers a baby girl should be counselled about the consequences of her daughter being cut. The husband/partner and any family members who are influential in decisions about FGM should also be counselled about the same issues.

5.6

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## DEINFIBULATION

# After reading this chapter you should be able to:

- Understand deinfibulation, how and when to perform the procedure, and the necessary follow-up
- Recognize the indications and contraindications for deinfibulation
- Understand how to provide counselling and information about the procedure to your female patients and their family members, if appropriate
- Understand the psychological and physiological aspects of deinfibulation and how to address them





## 6.1 DEINFIBULATION: INDICATIONS AND CONTRAINDICATIONS

Deinfibulation is a surgical procedure that reverses infibulation by opening up the closed genital scar tissue in a girl or woman who has undergone type III FGM. It is often necessary for improving health and well-being as well as to allow intercourse or to facilitate childbirth (1).
#### 6.1.1 DISCUSSING DEINFIBULATION WITH GIRLS AND WOMEN LIVING WITH FGM

The need for deinfibulation should be discussed in detail with girls and women who have undergone type III FGM.

In the case of pregnant women who have undergone type III FGM, the need for deinfibulation should be discussed in detail as early as possible during the antenatal period in order to allow the woman to reach an informed decision about the procedure and develop an adequate birth plan (see Chapter 5, section 5.4).

WHO RECOMMENDATION

WHO recommends deinfibulation for preventing and treating obstetric complications in women living with type III FGM (1).

#### **6.1.2 INDICATIONS FOR DEINFIBULATION**

Opening up an infibulation is indicated in a range of circumstances. These include:



personal choice of the woman;

during the second trimester of pregnancy or during labour to allow childbirth;

to facilitate gynaecological procedures requiring manual or speculum examination or treatment vaginally;

#### to treat conditions such as:

- urinary retention
- recurrent urinary tract infections and or kidney infections
- recurrent reproductive tract infections
- menstrual problems, such as haematocolpos and dysmenorrhoea (especially in adolescents)
- dyspareunia (painful sexual intercourse)
- difficult penetration during sexual intercourse
- incomplete abortion
- other gynaecological conditions such as cervical cancer;

#### to allow termination of pregnancy if needed; and

for the use of certain contraceptive methods.

# 6.1.3 CONTRAINDICATIONS FOR DEINFIBULATION

These include:



### 6.2 DECISION-MAKING FOR DEINFIBULATION

You must always offer comprehensive information and counselling to women prior to deinfibulation – and to their husbands/ partners also, if appropriate. Ideally, this counselling should take place before or during pregnancy so that the woman has time to confidently reach an informed decision about whether and when to have the deinfibulation procedure.

#### DECIDING WHEN TO DEINFIBULATE: COLLABORATIVE DECISION-MAKING

If during the antenatal assessment you confirm that deinfibulation is needed, you must first communicate this to the woman and then discuss with her the options for the timing of the procedure. It is the woman's choice to decide if she would like to undergo the procedure and when. The options for the timing of deinfibulation include:

#### • antepartum

(during pregnancy – preferably during the second trimester) OR

### • *intrapartum* (during the first stage of labour or during childbirth).

Both antepartum and intrapartum deinfibulation have advantages and disadvantages (see Boxes 6.1 A and 6.1 B). Discuss these with the woman to help her reach an informed decision.

#### WHO RECOMMENDATION

Either antepartum or intrapartum deinfibulation is recommended to facilitate childbirth in women living with type III FGM, depending on the context (1).

#### BOX 6.1 A Deinfibulation during pregnancy (antepartum)



#### **ADVANTAGES**

- It facilitates several medical procedures required during pregnancy and labour:
  - performing vaginal examination if needed
  - obtaining clean samples of urine
  - investigating conditions such as vaginal infections, premature rupture of membranes and antepartum vaginal bleeding if they occur.
- It allows time for healing before childbirth.
- It gives the woman time to adjust to the physiological changes after deinfibulation
  (see Box 6.3 in section 6.3). → 6.3
- The woman will arrive at childbirth with an unobstructed vaginal opening.

#### DISADVANTAGES

- It requires performing a minor surgical procedure during pregnancy.
- The woman will need to return to the healthcare facility for postoperative follow-up.
- Women must be able to rest and take good care of the wound for a week after the procedure.



#### BOX 6.1 B Deinfibulation during labour (intrapartum)



#### **ADVANTAGES**

- If deinfibulation was not advisable or not performed during pregnancy, this will be the only opportunity to open the infibulation in a woman with type III FGM in order to facilitate unobstructed vaginal childbirth.
- It facilitates the evaluation of the progression of labour, and also facilitates medical procedures required during childbirth.

#### DISADVANTAGES

- Anatomical conditions that arise during labour, such as tissue oedema and distortion, may pose difficulties when performing intrapartum deinfibulation – especially for less-experienced health-care professionals (1).
- There is a risk of injuring the baby during the procedure.
- While dealing with the pain of contractions during labour, it may be difficult for the woman to keep still during the deinfibulation procedure.
- In cases when labour progresses fast, there may not be time to perform deinfibulation.
   This puts women at risk of severe perineal tears.



#### **ADDITIONAL FACTORS**

Additional factors to consider when discussing the timing of deinfibulation with the woman include the following.

- In contexts where the woman may not give birth in a health-care facility, encouraging her to undergo deinfibulation during pregnancy will ensure that she has the procedure done before giving birth.
- In health-care facilities with a high patient load it may be difficult to closely monitor the progression of labour and determine the right moment to perform deinfibulation; in these cases, antepartum deinfibulation would be preferable.

#### **REMEMBER:**

Women who wish to be deinfibulated during labour/childbirth rather than during pregnancy should be advised to give birth in a hospital.

Always clearly document the woman's decision in the medical record.

#### **IMPORTANT!**

If the woman chooses to be deinfibulated during pregnancy, it is preferable to carry out the procedure during the second trimester of pregnancy (between the 20th and 28th weeks of pregnancy).

Preferably you should not perform deinfibulation during the first trimester of pregnancy, as during this period there is generally an increased risk of spontaneous abortion. If a spontaneous abortion occurs after a first-trimester deinfibulation, the woman may blame the procedure for the miscarriage. This may lead to a false belief that deinfibulation is a dangerous procedure (2).

### 6.3 COUNSELLING FOR DEINFIBULATION

All women should receive information and counselling before deinfibulation. However, if there is not sufficient time to discuss the surgical intervention in detail – for example, if a woman arrives at the health-care facility already in advanced labour – you should explain the procedure as you perform the deinfibulation and then provide additional details and rationale following childbirth.

#### COUNSELLING SESSION CHECKLIST

#### **1** In preparation for the counselling session

Find a quiet and private place to speak.

✓ If the woman speaks a different language, call in an interpreter (see Chapter 2, section 2.4). Make sure the interpreter is acceptable to her.

## **2** Discussing the effects of infibulation and the benefits of deinfibulation

Start the counselling session by giving the woman information about the effects of type III FGM in general, and its effects on pregnancy and childbirth.

Educate her about the anatomy and physiology of the female reproductive system. Make her aware of the difference between uncut and infibulated genitalia and the anatomical changes she can expect. If the woman agrees, show her images and drawings that can help describe these (see section 1.3 in Chapter 1 or Job aid I).

Give her (and her husband/partner if he accompanies her) detailed information about the physiological changes that will occur in functions such as urination and sexual intercourse (see the checklist in Box 6.3). Provide information about difficulties and complications associated with infibulated genitalia during pregnancy and childbirth and the importance of opening up her infibulation to prevent these.

Highlight the positive effects of deinfibulation on her health and the reduction in risk to the health of the newborn during childbirth (see Box 6.2 below).

**Inform** her of the legal status of FGM in the country where she is living (and presumably where she intends to give birth).

#### BOX 6.2 Discussing the benefits of deinfibulation

It will be easier to monitor your pregnancy to make sure your baby is developing well.

By removing the obstruction that covers your vaginal opening, it will make childbirth easier for you and your baby.

Urine and menstrual blood will exit your body more easily and less painfully.

If you experience pain during sexual intercourse, deinfibulation can help make sex more comfortable for you and your husband/partner.

#### BOX 6.3 Physiological changes after deinfibulation

After deinfibulation, the following physiological changes can be expected.

- Urine will flow more quickly in a larger stream.
- Menstruation may appear to be heavier.
- There may be a temporary increase in sensitivity in the vulvar area.
- There may be increased vaginal discharge and humidity during parts of the menstrual cycle.
- The appearance of the vulvar area may change (the area will appear more reddish in colour, similar to the colour of the mouth).
- A wider vaginal opening may result in different sensations during sexual intercourse for the woman and her husband/ partner.

Reassure the woman that it is normal to experience these changes, especially initially after being deinfibulated.

Remember to discuss potential false beliefs about deinfibulation and remind her that deinfibulation does not affect her baby during pregnancy.

#### **3** Providing information about the procedure

**Explain** the deinfibulation procedure to the woman and make sure she has fully understood what it entails. Also inform her that the edges of the labia will be sutured separately, and not re-sutured together. Job aid III provides a set of illustrations that you can use when explaining the deinfibulation procedure (the illustrations are also in section 6.4).

**Explain** carefully to the woman and her husband/partner that the procedure will lead to the complete opening of the stitched labia, and advise them that the procedure should only be done once (requests for a "mini" deinfibulation should be declined).

**Explain** that the procedure will be done under local anaesthesia and discuss postoperative pain relief options. Reassure the woman that all efforts will be made so she does not feel pain during or after the procedure (deinfibulation will not hurt as much as the original FGM procedure).

#### WHO RECOMMENDATION

Girls and women who are candidates for deinfibulation should receive adequate preoperative briefing (1).

#### 4 Counselling against re-infibulation

✓ In countries where there are laws against re-infibulation, it is relatively simple to deal with requests for closing up an opened infibulation, since you can explain that the law does not allow re-suturing. But in countries where there are no such laws, a request for re-suturing can pose a difficult dilemma. In such a situation, you should follow the guidelines of the health-care facility or health institution. However, whatever the legal status of FGM or re-infibulation, every effort should be made to discourage the practice of re-infibulation. Counselling and education about this issue will help you achieve this.

**REMEMBER:** A woman, and sometimes her husband/partner or family members, may request that she be re-infibulated after childbirth. It is part of your role as a health-care provider to provide information about the health risks of re-infibulation and the benefits of not re-infibulating (1).



**Re-infibulation:** A procedure to narrow the vaginal opening again in a woman who has been deinfibulated. If it is done, it is usually done after childbirth. It is also known as "re-suturing".

Reassure and remind the woman about the health benefits of deinfibulation and highlight the risks of re-infibulation (see Boxes 6.2 and 6.4).

Make sure you consider the woman's feelings and apprehensions regarding deinfibulated genitalia. For example, she may fear her husband's negative perceptions of deinfibulation and the possible consequences for her marriage or sexual intimacy.

Let her know that you are available to discuss the issue with her husband/partner or family members if this is needed.

## 5 Addressing a woman's resistance to deinfibulation

Reassure the woman that you are willing to discuss the situation with her husband/partner and/or anyone else she wishes. They may need additional information or wish to discuss it as well. They should be informed about the deinfibulation procedure, the importance of keeping the genitalia open, and the health consequences and risks of closing them again.

If the woman is concerned about disagreement from her husband/partner/family, you can offer to provide her with a note stating the medical indications for deinfibulation – this may help her to obtain their support.

Make sure you complete the required records and documentation accurately. Include notes saying that you provided counselling. It is very important that you state whether the woman reached a decision, what she decided and, if she agreed to be deinfibulated, that she gave her consent for the procedure.

#### BOX 6.4 The risks of re-infibulation

Re-infibulation is never medically recommended.

, It is a painful and unnecessary procedure.

- It can cause severe health problems to the mother during the postpartum period – including pain, infections and obstruction to the urinary flow and vaginal secretions – and in future pregnancies.
- Children born in future pregnancies will be at risk of difficult labour.

It is illegal in several countries in the world.

It is a violation of the woman's human rights.



## 6.4 DEINFIBULATION: THE PROCEDURE FOR OPENING UP TYPE III FGM

**IMPORTANT!** Opening up an infibulation should only be done after the woman has been thoroughly counselled and has given consent (unless it is an emergency situation when the woman is already in advanced labour; see section 6.3).  $\rightarrow$  6.3

If the woman is married or in a partnership, it is important to counsel the husband/partner as well, both as a couple and, if necessary, by himself. It is important to assist both in dealing with the resulting changes that will be experienced during sexual intercourse after deinfibulation. See section 6.3 for details on counselling for deinfibulation.  $\Rightarrow 6.3$ 

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#### **6.4.1 IN PREPARATION FOR THE PROCEDURE**

#### Explain...

In order to prepare the woman (and her husband/partner if appropriate), give clear and full information about the procedure and make sure she has understood. Ask the woman if she has any questions.

#### Preparation of equipment and materials

Prepare a tray with:

- a pair of sterile gloves
- antiseptic swabs and dressings
- a pair of straight Metzenbaum scissors or curved Mayo scissors (depending on the thickness of the tissue)
- a pair of suture scissors
- a pair of surgical tweezers
- a dilator (if available)
- two artery forceps
- a needle holder
- sterile swabs
- 10-ml syringe and needles for injection
- local anaesthetic (such as Lidocaine)
- 3-0 absorbable suturing material
- sterile towel/surgical cloth
- antiseptic solution
- a receptacle for used instruments.

#### 6.4.2 THE DEINFIBULATION PROCEDURE

- Ask the woman to lie on her back on the examining table.
- Wash your hands and put on gloves.
- Expose the genitalia and clean the perineal area with antiseptic swabs.

Use medicated soap and water or alcohol-based handrub for hand hygiene (2,3).

- Start by palpating the scar tissue in order to identify underlying structures (urethral meatus). This will help guide the procedure.
- Gently introduce your index finger or both your index and middle fingers – or a dilator – under the hood of skin anteriorly and slightly lift the scar tissue (see Figure 6.1).







Figure 6.2

6

Infiltrate local anaesthetic into the area where the cut will be made, along and on both sides of the scar (if the woman has received epidural anaesthesia there is no need to administer local anaesthetic) (see Figure 6.2).

With your finger or dilator under the scar, carefully introduce the scissors in front of your finger and cut the scar alongside your finger to avoid injury to the adjacent tissues (or to the baby, if the procedure is done during childbirth) (see Figures 6.3 and 6.4).

The cut should be made along the mid-line of the scar towards the pubis to expose the urethral opening.

Do not incise beyond the urethra. Extending the incision forward may cause haemorrhage.

**IMPORTANT!** Take care not to cause injury to the structures underneath the scar (urethra, labia minora and clitoris). It is possible with type III FGM to find these structures below the scar intact.





Figure 6.4

- 8 **Inspect** the cut edges for bleeding points and perform haemostasis if needed. Generally speaking, there is little bleeding for the relatively avascular scar tissue.
- 9 Suture the raw edges separately with individual stitches. Use fine 3-0 plain, absorbable suturing material to secure haemostasis and prevent adhesion formation (see Figures 6.5 and 6.6).
- **Prescribe** oral analgesia following the deinfibulation.







Figure 6.6



An online surgical video on deinfibulation is available at the following link (4): (Courtesy of Dr Jasmine Abdulcadir)



#### 6.4.3 POSTOPERATIVE CARE

Following deinfibulation, the woman should remain in the health centre for 2–4 hours, in order that a health-care provider can closely monitor potential bleeding and the woman's postoperative pain level. Upon discharge, postoperative care should include the following steps.

### Analgesia... 🖌



- **Provide** oral analgesia according to local protocols.
- Acetaminophen 500 mg, 3 times a day, can be offered to women who undergo deinfibulation during pregnancy.
- Many women report increased sensitivity in the vulvar area which was covered by the scarred skin for 2-4 weeks following the procedure. Suggest that she takes sitz baths (a bath in which a person sits in warm water containing salt) up to three times a day followed by gentle drying of the area. Application of a soothing cream can be prescribed for the first 1–2 weeks.



Advise the woman and her husband/partner that sexual intercourse should only be resumed once the woman feels ready and the wound has had adequate time to heal. Typically, this will be after 4–6 weeks. This may require counselling over several sessions.

**IMPORTANT!** Advice and counselling regarding sexual matters require great sensitivity, and should be carefully tailored according to the needs of the woman and to what is culturally appropriate.

- **Instruct** the woman on the importance of vulvar hygiene, and the need to keep her vulva clean and dry (see the box on "Discussing correct vulvar hygiene" in section 5.3.1).
- **Explain** the importance of maintaining the vulvar edges separated to avoid postoperative adhesions.
- **If absorbable stitches were used, warn** the woman that it is normal to see and feel stitches in the vulvar area. Tell her that these stitches need not be removed, as they will disappear on their own after a week.

**NOTE ON FOLLOW-UP:** *If possible, make an appointment for a follow-up visit after one week, to monitor the healing process. You may also offer her the option of coming to the health centre for daily wound care during the first week, if feasible.* 



Ask the woman if she has any additional questions.

**NOTE OF REFERRAL**: In cases where the woman is referred to a different health-care facility for follow-up, you must provide a clear referral note to the health-care provider who will be responsible for follow-up to ensure continuity of care.

#### References

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- Female genital mutilation: integrating the prevention and the management of the health complications into the curricula of nursing and midwifery: a teacher's guide. Geneva: World Health Organization; 2001 (http://www.who.int/ reproductivehealth/publications/fgm/RHR\_01\_16/en/, accessed 23 November 2017).
- 3. Johnson C, Nour NM. Surgical techniques: defibulation of type III female genital cutting. J Sex Med. 2007;4(6):1544-7.
- Abdulcadir J, Marras S, Catania L, Abdulcadir O, Petignat P. Defibulation: A visual reference and learning tool [video]. J Sex Med. 2018;15(4):601-611. (https://www. youtube.com/watch?v=XRid7jIUzMY&t=3s, accessed 19 April 2018.



### MENTAL HEALTH & FGM

## After reading this chapter you should be able to:

- Understand why FGM can result in mental health problems and disorders
- Understand the role of the health-care provider with regard to the mental health of women who have undergone FGM
- Conduct a mental health assessment as part of routine care in any clinical setting
- Identify common mental health problems and disorders associated with FGM
- Provide immediate psychological support for girls and women who have experienced FGM and/or physical problems related to FGM
- Discuss and decide on management options with your patient, and decide whether or not a referral is needed for further treatment or support

#### In this chapter



## 7.1 THE IMPORTANCE OF ADDRESSING MENTAL HEALTH

Mental health problems and disorders are common in the general population. An estimated 30% of adults will experience a common mental health disorder in their lifetime (anxiety, depression or post-traumatic stress disorder [PTSD]) (1), and up to 50% of patients presenting in primary health care settings may have mental health problems (2).

This chapter will help you to distinguish between signs of three levels of mental distress: (i) normal distress, (ii) mental health problems (symptoms that are of clinical concern and for which people may want help) and (iii) mental health disorders.

#### THE ROLE OF NON-SPECIALIST PROVIDERS

For the following reasons, it is important that mental health problems and disorders are initially assessed and managed by non-specialist health-care providers in all health-care settings.

- A holistic approach that explores both the physical and mental health of a person is the best approach to health care.
- Research has shown that, with brief training, health-care providers can identify and manage mental health problems and improve physical and mental health (3,4).
- People are more comfortable receiving help in a primary health care setting because it is much more accessible and less stigmatizing than attending a specialized clinic (5).



**Mental health problems:** This term is used for those mental health difficulties that cause distress and require support, but which don't meet the criteria for a disorder.

**Mental health disorders:** This term refers to more severe clusters of symptoms that match a commonly recognized pattern and follow a predictable course (as with physical disorders).

### 7.2 MENTAL HEALTH PROBLEMS & DISORDERS ASSOCIATED WITH FGM

For girls and women who undergo FGM, genital cutting can be a traumatic experience that may leave a lasting psychological mark and adversely affect their mental health (6). FGM may have both immediate and prolonged negative psychological consequences.

#### MENTAL HEALTH IMPACT OF FGM

Pain, shock and the use of physical force by those performing the procedure have been mentioned as reasons why many women describe FGM as a traumatic event (7). The physical and sexual health complications that may arise after FGM can also have negative psychological consequences, as can any surgical procedures to address them (8).

Studies have found that FGM is associated with a range of mental health problems, some of which may be normal reactions to traumatic events. These problems include: irritability and frustration, flashbacks and nightmares, feelings of low self-esteem, fear, paranoid thoughts (e.g. a false belief that... someone is persecuting or trying to harm you), sleep problems, obsessive-compulsive tendencies (see section 7.5.2), **2**.5 as well as relationship problems and psychosexual difficulties, which are addressed in Chapter 8 of this handbook (8-11).

Studies have found that girls and women who have experienced FGM may have higher rates of mental health disorders *(12,13)*, particularly:

- depression
- anxiety disorders
- post-traumatic stress disorder (PTSD)
- somatic (physical) complaints with no organic cause (e.g. aches and pain).

The psychological impacts of FGM have not been widely researched, but what is known is that they are enormously varied. Not all girls and women who have experienced FGM will have psychological difficulties. Their response is affected by:

- sociodemographic characteristics (i.e. culture, socioeconomic background, ethnicity, education, age);
- whether the patient is living in her community of origin or is a migrant;
- the acceptability of the practice in the community and society where she is living;
- the attitudes of health-care providers; and
- the legality of FGM in the place where she is living.

Health-care providers will need to understand a patient's background, beliefs and social context in order to find the best way to discuss FGM, to help the patient make sense of how she is feeling, and to advise and support her in the best management plan (13,14).

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**IMPORTANT!** It is very important not to pathologize normal sadness and anxiety in women who have experienced FGM. They are as likely as anyone to experience the full range of emotions in response to life events. However, it is important to recognize that they have experienced a traumatic event.
## **CASE VIGNETTE 1**

This quote shows the suffering that women who have been cut may experience.

"Because this is about feelings and more than that; it is about sex. You cannot share that with other people. You feel terribly embarrassed. That is why excised women become isolated, mentally ill or mad. Either that or she stops talking; she keeps her mouth firmly shut. And nobody understands why. It sounds shallow, but it goes really deep. The difference is that a woman who has been cut will blame any pain she feels on the excision. That is all we know. And because we feel ashamed, we stay home with our problems" (14).

- A divorced Eritrean mother of seven, living in the Netherlands

## ASSESSING THE 7.3 MENTAL HEALTH OF WOMEN LIVING WITH FGM

A mental health assessment is necessary for all women living with FGM, and should therefore be part of the routine assessment by a health-care provider because:

- Physical problems can cause mental health problems, or make them worse.
- Mental health problems can make physical problems worse.
- Women who have undergone FGM have experienced a traumatic event.
- Female patients may have mental health problems that are not related to FGM.
- Mental health problems are common.

It is not difficult for a health worker to include a mental health assessment during initial history-taking and clinical examination. We make judgements quite naturally every day about the mental state of people we encounter, whether they are friends or strangers, by observing their facial expressions, tone of voice and behaviour. For example, if someone looks sad or tearful we might ask, "How are you feeling today? You look very sad."

**REMEMBER:** Make sure your patient feels welcomed and let her know that as a health-care provider your role is to provide support and care.

For detailed advice on initiating discussion on the topic of FGM, see Chapter 2: Communicating with girls and women living with FGM.  $\bigcirc$  2



## 7.3.1 INITIAL MENTAL HEALTH ASSESSMENT

You can easily decide whether your patient needs a full mental health assessment by first taking the following steps during the initial history-taking and routine general health assessment.



Ask... ?

After finishing your general health assessment, during which you will have made some observations, **ask** your patient directly about her mental health, using culturally appropriate questions about her thoughts, perceptions and cognition (see below).

THOUGHTS	<ul> <li>Does she have thoughts about hurting herself?</li> <li>Are there bad thoughts or memories that keep coming back?</li> <li>Is she seeing the event over and over in her mind?</li> </ul>
PERCEPTIONS	<ul> <li>Does she see, hear, smell or feel things that others cannot see, hear, smell or feel?</li> </ul>
COGNITION	<ul> <li>Does she have any difficulties with concentration, attention or memory?</li> <li>Does she know where she is, the time of day, week, month, and the names of familiar people?</li> </ul>

**Ask** about her mood, behaviour, relationships with others, daily functioning, sleep, appetite, energy, etc.

**Ask** about somatic complaints with no organic cause, such as headaches or back pain (if this was not already covered during a general health assessment).

The example questions on the following page may help you ask your patient about these aspects.

Aside from the health problems we have just discussed, how do you feel today?

Do you feel like you are thinking too much? Do your thoughts come too fast, or too slow?

How are you getting along with other people (e.g. partner, family members, friends, co-workers)?

How are you managing with school/work/household tasks?

Do you have headaches or any other aches and pains?

Are there any other specific symptoms you would like to tell me about? For example, do you have any particular fears or worries, or unusual or upsetting thoughts or experiences?

If your observations or your patient's answers to any of the questions listed above or in the previous steps concern you, your patient may have a mental health problem or disorder: conduct a full mental health assessment as described in the following section. Reassure...

6 **Reassure** your patient that mental health problems are very common in the general population, that it is not unusual for women with FGM to experience distress and shame around this, and that often this distress is normal.

• **Remind** her that your discussion is confidential and that she is not being judged. Acknowledging problems makes them easier to address. This may help her speak about her distress.



#### **ENSURE SUFFICIENT TIME**

Ideally, the history-taking and initial mental health assessment will all be completed in one session, so make sure there is enough time.

If there really isn't enough time, then it is best to make another appointment, instead of starting a mental assessment and not being able to finish it. This is because talking about FGM and psychological issues requires time and sensitivity; this also shows the patient that you are taking her seriously and are genuinely interested in her problems.



## 7.3.2 FULL MENTAL HEALTH ASSESSMENT

A full mental health assessment includes the following steps.

- 1. Description of the current problem
- 2. Previous history of mental health problems
- 3. General health history
- 4. Family history of mental health problems
- 5. Psychosocial history
- 6. Mental state examination

## Description of the current problem

If your patient has mentioned any symptoms that concern you, or you have observed anything unusual about her during your initial examination (see section 7.3.1), you will need to ask for more details. → 7.3 This includes asking the woman to explain to you her understanding of when, why and how the mental health problems began, followed by more detailed enquiries about her symptoms. For example, you can ask:

Can you tell me more about these unpleasant symptoms you are experiencing?

Did you have similar problems prior to the FGM?

Have the symptoms changed over time? In what way?

Are the symptoms triggered or made worse by any particular things (such as thinking about sexual relationships and pregnancy)?

Do you avoid any situations to prevent the symptoms occurring?

#### **REMEMBER:**

You can enquire about the symptoms and problems associated with a traumatic event (such as FGM) without insisting that your patient tell you about the actual event.

Do not force your patient to discuss the details of the FGM experience or any other traumatic event if she does not want to. You can say, for example:

I understand you had an experience which was painful and distressing. If you want to discuss the details further you are welcome to do so, now, or at any other time, but there is no need to discuss it if you find it too upsetting. What I would like to understand today is how that experience is affecting you now? Is it causing any problems or symptoms?

## Previous history of mental health problems

**Ask** about any mental health problems or disorders your patient has experienced in the past, any related hospitalizations, and any prescribed medications.

### Suicide risk and self-harm

**Explore** possible thoughts and attempts of suicide and self-harm. For example, you can ask:

What are your hopes for the future?

If she expresses hopelessness, ask further questions such as:

Do you feel that life is worth living?

Do you think about hurting yourself, or have you ever hurt yourself deliberately?

Have you made any plans – or have you ever tried – to end your life?

#### COMMON MISCONCEPTIONS ABOUT SUICIDE

Some health workers fear that asking about suicide may provoke a patient to commit it.

On the contrary, talking about suicide often reduces the anxiety the patient has around suicidal thoughts and helps her feel understood.

#### BOX 7.1 Imminent risk of suicide and self-harm

#### If your patient has:

· current thoughts or plans about committing suicide or harming herself

OR

 a history of thoughts or plans about suicide or self-harm in the past month, or acts of self-harm in the past year, and she is now extremely agitated, violent, distressed or uncommunicative

THEN there is imminent risk of self-harm or suicide, and she should not be left alone. Refer her immediately to a mental health specialist or emergency health-care facility.

#### **ADDITIONAL RESOURCES**

For further information about how to address self-harm and suicidal thinking, refer to the relevant module in the *mental health Gap Action Programme (mhGAP) Intervention guide for mental, neurological and substance use disorders in non-specialized health settings – version 2.0* 



### Substance abuse

Ask your patient about tobacco, alcohol and drug use.

Questions regarding alcohol and drugs can be perceived as sensitive and offensive. **Explain** to the woman that this is part of routine health assessments and try to ask questions in a non-judgemental and culturally sensitive way. For example, you can say:

I need to ask you a few routine questions as part of the assessment. Do you drink alcohol/use khat (or any other substance known to be a problem in the area)? [If yes] How much per day or per week?

> Do you take any tablets when you feel stressed, upset or afraid? Is there anything you use when you have pain? Do you take sleeping tablets? [If yes] How much/many do you take per day/week? Since when?

### **3** General health history

If the presenting problem is a mental health problem, it is equally important to include questions about the patient's physical health and to do a physical examination.

- Ask about physical health problems, surgical interventions and medications.
- Obtain a list of current medications. Ask about allergies to medications.

## **4** Family history of mental health problems

- Ask your patient about any family history of mental health problems or disorders.
- Ask if anyone in the family has had similar symptoms or has received treatment for a mental health problem or disorder.

### Psychosocial history

- If not already covered during patient registration/history-taking, obtain basic information, including where the woman lives, her level of education, work/employment history, income, migration history and status, marital status and the number/ages of her children, as well as who lives in her household and what the living conditions are like.
- Ask about current stressors, coping methods and social support. For example, you can ask:

Are there additional problems, worries or stresses in your life at present? Can you tell me about these?

What kind of things have you tried to make yourself feel better? Have they helped?

Have you tried any medication? If so, what kind (e.g. prescribed, non-prescribed, herbal)? What effect did it have?

Who do you turn to for support? Are friends, family, members of the community helpful?

• Ask about current functioning at home and at school/work.

How does this problem affect your daily and family life?

How does this problem affect you at school/work or in daily community/social life?

• For children and adolescents, **ask** whether they have a parent or carer, and ask about the nature and quality of that relationship, and how they are getting on at school and with friends. If possible, ask the parents or carer if the child's behavior has changed recently; for example: Is she more naughty or clingy? Does she behave like a younger child?

#### 6 Mental state examination

The mental state examination (described in section 7.3.1) may have already been conducted at the same time as the general health examination, unless the presenting problem was a mental health one.

**REMEMBER:** A comprehensive mental health assessment always includes a mental state examination, which uses careful observation and listening as its main methods, combined with asking some straightforward additional questions (refer to information in section 7.3.1).



### 7.3.3 ASSESSMENT RESULTS AND NEXT STEPS

If, as a result of your initial and full assessments, you suspect a mental health problem, then use section 7.4 "Basic mental health care for women living with FGM" to help you provide basic management and support.  $\bigcirc$  74

Some patients may have a mental health disorder such as depression, anxiety or post-traumatic stress disorder (PTSD), and thus may need further assessment and more advanced management, which is covered in section 7.5.  $\bigcirc$  <sup>75</sup> The information in Box 7.2 on the next page will help you decide whether or not you should suspect a specific mental health disorder and, if so, which part of section 7.5 will provide the most relevant guidance on further assessment and management.  $\bigcirc$  <sup>75</sup>

For information on assessment and management of other mental health problems, refer to section 7.6.  $\rightarrow$  7.6

#### ADDITIONAL RESOURCES

Details on the assessment and management of all the problems and disorders mentioned in sections 7.5 and 7.6, and on other common mental health problems, can be found in the *mental health Gap Action Programme (mhGAP) Intervention guide for mental, neurological and substance use disorders in non-specialized health settings (version* 2.0), and in the module on *Assessment and management of conditions specifically related to stress (version 1.0).* 

### BOX 7.2

## Where to find further information on specific mental health disorders

If a patient of any age has one or more of the listed symptoms/features, conduct further assessment for the associated disorder(s).

Common presentation	Possible disorder
<ul> <li>Multiple persistent physical symptoms with no clear cause</li> <li>Low energy, fatigue, sleep problems</li> <li>Persistent sadness or depressed mood, anxiety</li> <li>Loss of interest or pleasure in activities that are normally enjoyable</li> </ul>	<b>DEPRESSION</b> For more information see <b>section 7.5.1 7.5</b>
<ul> <li>Excessive feelings of fear, worry, irritability, frustration and anxiety without an apparent cause</li> <li>Limitations on daily activities because of these feelings</li> <li>Avoidance of particular places because of these feelings</li> </ul>	ANXIETY For more information see section 7.5.2 $\rightarrow$ 7.5
<ul> <li>Frightening dreams, flashbacks or intrusive memories of a traumatic event</li> <li>Deliberate avoidance of thoughts, memories, activities or situations that remind the patient of the traumatic event</li> <li>Feeling hyperalert to any threat and/or reacting strongly to unexpected sudden movements (e.g. being "jumpy" or "on edge")</li> </ul>	POST-TRAUMATIC STRESS DISORDER (PTSD) For more information see section 7.5.3 $\rightarrow$ 7.5

## 7.4 BASIC MENTAL HEALTH CARE & SUPPORT FOR WOMEN LIVING WITH FGM

Health-care providers in primary health care settings are best positioned to provide basic psychological support when patients present with any kind of mental distress (whether it is normal distress, a mental health problem or a mental health disorder). The main skills needed are empathy and an ability to listen. The very fact that the patient is seeking care indicates a degree of trust in you as a health-care provider, and suggests that the patient is going to be receptive to the advice you give.

## **BASIC MENTAL HEALTH SUPPORT**

In this section you will find six simple techniques that will allow you to provide basic psychological support to your patients, including women who have undergone FGM.

- 7.4.1 Providing psychoeducation
- 7.4.2 Reducing current stressors
- 7.4.3 Teaching and encouraging the use of stress-reduction techniques
- 7.4.4 Increasing positive coping
- 7.4.5 Promoting functioning in daily activities
- 7.4.6 Strengthening social support

You will also find advice on how to teach your patients to apply these techniques during *any* consultation, even if you have not diagnosed any kind of mental health problem and even if they are seeking health care for other concerns or symptoms.

## 7.4.1 PROVIDING PSYCHOEDUCATION

Psychoeducation refers to the process of providing education and information to those seeking or receiving mental health services, to help them better understand and cope with mental health problems. People may worry about discussing their feelings of emotional distress for a number of reasons: they may be concerned that it indicates weakness on their part, that people will think they are "going crazy", and that they will suffer from associated stigma. Some people may believe their symptoms result from spirits or bewitchment and may be shy to discuss these beliefs with a healthcare professional. The patient's feelings/symptoms, her beliefs about them, and/or her reluctance to discuss them are likely to cause substantial anxiety and stress.

As a first step in providing basic support, psychoeducation is an important way of reducing distress by discussing and explaining the symptom(s) and the treatment options.

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**IMPORTANT!** Psychoeducation must be provided in a way that is respectful, non-judgemental and sensitive to the patient's concerns and beliefs.

#### THE THREE STEPS OF PSYCHOEDUCATION

- Ask your patient about her understanding of the problem. To initiate the psychoeducation session, you can respectfully ask your patient about her own understanding of the problem, its causes and possible treatment.
  - **Give the possible medical explanation of the symptom/ problem.** Explain to your patient what the unpleasant symptom or disorder (mental or physical) is.
  - **Provide information about the best options for treatment.** When presenting the treatment options, also emphasize the need to adhere to the agreed treatment, and describe the likely results, including the time needed for recovery (see sections 7.5 and 7.6 for more information on specific disorders).  $\rightarrow$  7.5  $\rightarrow$  7.6

*If medication is being prescribed for any problem – mental or physical – this is a good opportunity to emphasize the need to take it as prescribed, and to discuss potential side-effects (short- and long-term) and the need to monitor these.* 

*If medication has been prescribed by another provider or specialist, make sure they covered this information and that the patient understands it.* 

If other carers or agencies are going to be involved, this is an opportunity to ensure that everyone understands the problem in the same way and agrees to the same plan.

## 7.4.2 REDUCING CURRENT STRESSORS

Mental health problems may be worse in women who are experiencing other forms of stress, especially those associated with migrating to another country (3), such as unemployment, social isolation, poverty and lack of control.

Discuss current stresses with your patient.

To explore these, you can ask questions like:

What other worries do you have at present?

What worries you most?

What are you doing to address these worries?

## **2** Advise on problem-management strategies.

Once additional stressors have been identified, your patient can adopt simple problem-management strategies to help her prioritize and cope with the major stressors.

To achieve this, help your patient to take the following five steps (this technique is also summarized in Job aid IV).

## $\mathbf{A}$ identify the key problem

- Make two lists:
  - problems that are solvable, and
  - problems that cannot be solved.
- Choose the most important problem from the "solvable" list.
- Clarify what the problem is and break it down into manageable parts.

## BRAINSTORM

## Assist the patient to generate possible strategies to address the problem

- Are there resources she can use?
- Are there people or agencies who can help?
- Are there other sources of support?
- What skills and strengths does she have that she can use to deal with the problem?
- Encourage her to come up with ideas; avoid giving her advice. You can ask her, for example: "If a friend had this problem, what would you advise her to do?"





## C CHOOSE WHICH STRATEGY OR STRATEGIES TO TRY

- Which would be the most effective?
- Which is easiest?
- Which one can she carry out (e.g. based on her financial means)?

#### TAKE ACTION AND USE THE STRATEGIES



- Make a detailed plan with your patient.
- Help her decide which strategy she will try first (if she has chosen more than one).
- Help her choose the best times and places to carry out the strategy (e.g. it may help if the planned actions coincide with routine activities).
- Discuss what she will need to take action (e.g. money, transportation, etc.).
- Discuss any possible obstacles.
- Create reminders (e.g. use a calendar/diary or other notes).

#### **REVIEW WHAT HAPPENED**

(This step should be done in a follow-up session.)

- What strategy worked well?
- What goals were achieved?
- What could be done better?
- What are the next steps?



## **REMEMBER:**

In general, do not give direct advice (e.g. "You should do X!") but instead try to encourage your patient to develop her own solutions (e.g. "What do you think you could try that might help?").

If that is not possible, consider giving some suggestions or ideas (e.g. "Some people say that X or Y can help, what do you think of that?").

## 7.4.3 TEACHING AND ENCOURAGING THE USE OF STRESS-REDUCTION TECHNIQUES

## Explain to your patient that stress has a direct physical effect on the body

Stress and fear produce a chemical messenger in your body called adrenalin. This rushes around your body and brain putting them in an alert state called the "fight or flight response", which can be useful or even life-saving in some situations (e.g. if we are in danger and need to escape or act to remove the danger).

But this alert state is not useful when the stressful event is over. It is like a fire alarm continuing to ring after the fire has stopped. It can cause muscle tension, heart palpitations, hyperventilation (breathing fast), dizziness and many other odd physical sensations, which can themselves also increase anxiety.

#### Invite your patient to try stress-reduction techniques

The two main techniques are slowing the breathing and learning to relax one's muscles (see instructions in Box 7.3). These are both simple techniques that are immediately effective in reducing anxiety and tension, so that the body returns to its normal state. If your patient is in a highly distressed and agitated state, using these techniques at the beginning of the session may enable you to assist your patient with thinking about and adopting other strategies, as appropriate (see section 7.4.2).

**NOTE ON FOLLOW-UP:** Stress-reduction techniques are best learnt by doing them during the initial session and practising them regularly in follow-up sessions, as well as encouraging daily practice at home, as needed.



**If your patient is a child**, teach the carer and child together. This will also be helpful in reducing the carer's stress.

## CULTURAL NOTE 🗢

Your patient may already know of traditional relaxation techniques from her own culture that she finds helpful. If they are beneficial, encourage her to use them.

## BOX 7.3 Exercises to help reduce stress

These exercises will help you to feel calm and relaxed. You can do them whenever you are stressed or anxious or if you cannot get to sleep. After learning to do these exercises, do them with your eyes closed.

#### A. SLOW BREATHING TECHNIQUE

- In this exercise, paying attention to the breath and slowing down your breathing helps to relieve stress.
- Sit on a chair with your feet flat on the floor, or sit or lie comfortably on the floor.
- Relax your body. Start by shaking your arms and legs then let them go loose. Roll your shoulders back and move your head from side to side.
- Put your hands in your lap or on your belly. Think about your breath.
- Slowly breathe out all the air through your mouth, and feel your belly flatten. Now breathe in slowly and deeply through your nose, and feel your belly fill up like a balloon.
- Continue to breathe slowly in this way, making sure the breath goes all the way to your belly. Your chest should not be moving. You can slowly count 1–2–3 on each breath in and 1–2–3 on each breath out.
- Keep breathing like this for about two minutes. As you breathe, feel the tension leave your body.



#### **B. PROGRESSIVE MUSCLE RELAXATION TECHNIQUE**

- In this exercise, you tighten and then relax different muscles in your body.
- Lie flat on your back. If this is not possible, you can do this in a sitting position.
- Begin with your toes. Curl your toes and hold the muscles tightly. This may hurt a little. Breathe in deeply through your nose and count 1–2–3 while holding your toe muscles tight. Then, relax your toes and let out your breath. Breathe normally and feel the relaxation in your toes.
- Do the same for each part of your body in turn. Each time, breathe deeply in as you tighten the muscles, count to 3, and then relax and breathe out slowly.
- Hold your calf muscles tight... 1–2–3... now relax.
- Hold your thigh muscles tight... 1–2–3... now relax.
- Pull in your behind... 1–2–3... now relax.
- Hold your belly tight... 1–2–3... now relax.
- Make fists with your hands... 1–2–3... now relax.
- Bend your arms at the elbows and hold your arms, biceps and triceps tight ... 1–2–3... now relax.
- Push out your chest... 1–2–3... now relax.
- Squeeze your shoulder blades together... 1–2–3... now relax.
- Shrug your shoulders as high as you can... 1–2–3... now relax.
- Tighten all the muscles in your face... 1–2–3... now relax.
- Now, drop your chin slowly towards your chest. As you breathe in, slowly and carefully move your head in a circle to the right, and then breathe out as you bring your head around to the left and back towards your chest. Do this three times. Now, go the other way: inhale as you move your head to the left and back, exhale as you bring it to the right and down towards your chest. Do this three times.
- Now bring your head up to the centre. Notice how calm you feel.

## 7.4.4 INCREASING POSITIVE COPING

After any traumatic experience – including the experience of FGM, a difficult pregnancy or childbirth experience, or a medical/surgical intervention – a girl or woman may find it difficult to return to her normal routines. Encourage her to take small and simple steps. Talk to her about her life and activities, particularly those aspects she previously found enjoyable.

Encourage your patient to:

- build on her strengths and abilities (e.g. ask what is going well currently, such as subjects in which she excels in school or aspects of work in or outside of the home that she enjoys, and how she has coped with difficult situations in the past);
- continue normal activities, especially ones that used to be interesting or pleasurable;
- engage in relaxing activities to reduce anxiety and tension;
- **keep a regular sleep schedule**, including getting enough sleep (7–8 hours per night) and avoiding sleeping too much;
- engage in regular physical activity;
- engage in regular contact with people whose company she enjoys and avoid isolating herself;
- avoid using self-prescribed medications, alcohol or illegal drugs to try to feel better;
- recognize thoughts of self-harm or suicide and come back as soon as possible for help if they occur (see Box 7.1 in section 7.3.2). 
   → 7.3

## 7.4.5 PROMOTING FUNCTIONING IN DAILY ACTIVITIES

When girls and women feel depressed or anxious or have become more isolated or withdrawn, they often stop doing their normal daily activities, such as attending school, going to work, taking the children out or doing the housework. Unfortunately, the less they do, the less they feel like doing and everything becomes a greater effort. A vicious cycle can develop, where worry or sadness result in lack of activity or staying home, which leads to more worry and sadness, or more anxiety about going out. This cycle needs to be interrupted by encouraging your patient to restart her normal routines, even when she does not feel like it.

- **Explain** that taking small steps to restart routines will make her feel better and it will get easier with each attempt.
- **Encourage** her to continue regular social, educational and occupational activities as much as possible.
- If needed, **encourage** your patient to continue her regular daily activities, such as leaving the house to shop for food, caring for her personal hygiene and clothing, and engaging in child care activities if she has children.

## 7.4.6 STRENGTHENING SOCIAL SUPPORT

Some women and girls who have experienced FGM state that they have become more isolated and withdrawn. This may be associated with feelings of anger, shame or guilt, particularly if they are migrants in communities or settings where they may have been exposed to media campaigns about the dangers of FGM or to negative attitudes from health workers and local community members (13,14).

Help your patient to identify supportive and trusted family members, friends and community members and to think through how each one can be involved in helping. For example, you can ask:

When you are not feeling well, who do you like to be with?

Who do you turn to for advice?

Who do you feel most comfortable sharing your problems with?

**IMPORTANT!** Explain to your patient that, even if there is no one with whom she wishes to share what has happened to her, she can still connect with family and friends. Spending time with people whose company she enjoys can distract her from her distress. Help her to identify past social activities or resources that may provide direct or indirect psychosocial support. These could be family gatherings, visits with neighbours, sports, community and/or religious activities. Encourage her to participate.

With your patient's consent, refer her to other community resources for social support. Social workers, case managers or other trusted people in the community may be able to assist in connecting the girl or woman with appropriate resources such as:

- community centres, self-help and support groups
- income-generating activities and other vocational opportunities
- formal or informal education
- structured activities for children and adolescents.

**NOTE OF REFERRAL:** When making a referral to another place, person or agency, help your patient to access these resources (e.g. provide directions to the location and information about operating hours and telephone number) and provide her with a short referral note.

#### ADDITIONAL RESOURCES

More detailed helpful advice, both on conducting a mental health assessment and on providing psychological support to adults impaired by distress, can be found in WHO's 2016 publication, *Problem Management Plus (PM+): individual psychological help for adults impaired by distress in communities exposed to adversity (15).* 



7.5 SPECIFIC MENTAL HEALTH DISORDERS: DEPRESSION, ANXIETY AND POST-TRAUMATIC STRESS DISORDER (PTSD) Section 7.5 describes further mental health assessment and support for patients with symptoms and signs indicative of depression, anxiety and PTSD. An estimated 30% of adults will experience one of these common mental health disorders in their lifetime (1).

This section is intended to guide health workers in providing further assessment if indicated after implementing section 7.3, and more advanced care than was covered in section 7.4, if needed. These three specific disorders will be addressed in turn in the following sub-sections.

# ASSESSMENT AND MANAGEMENT OF **7.5.1 DEPRESSION**

This section describes further mental health assessment and support for patients with symptoms and signs indicative of depression. It is intended to guide health workers in providing further assessment if indicated after implementing section 7.3, and more advanced care than was covered in section 7.4, if needed.
# I. WHAT IS DEPRESSION?

It is normal to suffer from sadness in response to upsetting life events and loss. However, if your patient has suffered from the following symptoms over a prolonged period, she may be suffering from a common mental health disorder called depression.

Depression is characterized by:

- persistent sadness, depressed mood and/or anxiety;
- loss of interest or pleasure in activities that are normally pleasurable;
- multiple persistent physical symptoms with no clear cause;
- low energy, fatigue and/or sleep problems.

#### **REMEMBER:**

Women living with FGM may be depressed for reasons that are not directly related to FGM. For example, one in six pregnant women and one in five women who have recently given birth are likely to experience a perinatal mental disorder (most commonly depression) (14). Prolonged physical illness and pain can be associated with depression, and depression can occur in some people without any reason (especially if there is a family history of this problem).



B

# II. ASSESSMENT FOR DEPRESSION

Assess your patient starting with the questions in set A, then proceed to B and C as needed.

# Core symptoms of depression

Ask your patient both of the following questions:

**#1** During the last month, have you often felt down, depressed or hopeless?

**#2** During the last month, have you often had little interest or pleasure in doing things?

# Additional symptoms of depression

If the answer is "yes" to one or both of the questions in A, then ask your patient:

During that last two weeks, have you experienced ...

- disturbed sleep or sleeping too much?
- significant change in appetite or weight (decrease or increase)?
- fatigue or loss of energy?
- reduced ability to concentrate on tasks?
- indecisiveness?
- agitation or physical restlessness?
- talking or moving more slowly than usual?
- feelings of hopelessness about the future?
- feelings of worthlessness or excessive guilt?
- suicidal thoughts or acts?

# Daily functioning

If the answer is "yes" to several items in B, then ask your patient:

How are you managing in your daily life...

- ... with your family and domestic activities?
- ... with your social activities?
- ... at work, school or other important areas of life?

If your patient answered "yes" to at least one question in A and several items in B, and if she is having considerable difficulties in any of the areas mentioned in C, she is probably suffering from depression.



However, before diagnosing and treating depression, it is important to rule out other possible explanations. Be sure to consider the three questions on the following page.

#### **OTHER POSSIBLE EXPLANATIONS**

#### Could your patient have another health condition?

Rule out any physical condition that can resemble or worsen depression: anaemia, malnutrition, hypothyroidism, stroke, and side-effects of medication or substance use (e.g. mood changes from steroids).

#### Could your patient have a history of mania?

A prior episode of mania is likely if several of the following symptoms occurred simultaneously, lasted for at least one week, and were severe enough to interfere significantly with daily functioning, or to require hospitalization or confinement:

- · elevated mood and/or irritability;
- decreased need for sleep;
- increased activity, feeling of increased energy, or rapid speech;
- impulsive or reckless behaviours (e.g. excessive spending, making important decisions without planning);
- loss of normal social inhibitions resulting in inappropriate behaviours;
- · racing thoughts, being easily distracted;
- unrealistically inflated self-esteem.

**NOTE OF REFERRAL:** If there is a history of mania, then the current episode of depression is probably part of another disorder called bipolar disorder, and your patient requires different management. Refer her to a mental health specialist.

# Could your patient be having a normal reaction to FGM or another distressing event?

If your patient has suffered a loss/bereavement or experienced a traumatic event (including FGM) in the last six months, it is more likely that she is having a normal reaction to an upsetting event rather than depression. She will still benefit from the psychological support techniques outlined in section 7.4.

# However, she should still be treated for depression if any of the following symptoms are present:

- suicidal ideation
- beliefs of worthlessness
- talking or moving more slowly than usual
- psychotic symptoms (hearing voices or experiencing unusual beliefs)
- · a previous history of moderate-to-severe depressive disorder.



# III. MANAGEMENT OF DEPRESSION

If, after completing the steps above, you conclude that your patient is suffering from depression, then consider the following points.

# Provide psychoeducation relevant to depression

Refer to section 7.4.1 for a basic description and outline of psychoeducation.  $\bigcirc$  7.4

Include the following points in your explanation to your patient.

Depression is a very common condition; it can happen to anybody.

Having depression does not mean that a person is weak or lazy.

- The negative attitudes of others towards someone with low mood (e.g. "You should be stronger", "Pull yourself together!") may reflect the fact that depression is not a visible condition (unlike a physical injury or scar) and the false idea that people can easily control their depression by sheer force of will.
- People with depression tend to have negative opinions about themselves, their lives and the future. Girls and women who have undergone FGM may have particular feelings of shame, guilt and/or worthlessness. These feelings are unjustified, but when she is depressed, these feelings can be worsened, making the girl or woman likely to withdraw and isolate herself. Explain that these

negative feelings and opinions and her self-esteem are likely to improve as her depression is managed.

Treatment takes time; it is likely to take a few weeks before she will feel any positive effects.



Advise your patient that, even if it is difficult, she should try to do as many of the following as possible to help improve her low mood.

 Continue to engage in activities that were previously pleasurable.

✓ Maintain regular sleeping and waking times.

Be as physically active as possible.

Eat regularly despite changes in appetite.

Spend time with trusted friends and trusted family members.

Participate in community and other social activities as much as possible.



If she notices any thoughts of self-harm or suicide, she should not act on them. She should tell a trusted person and come back for help immediately (see Box 7.1 in section 7.3.2).

# Support and assist your patient in reducing and coping with stress and strengthening her social support

Refer to the techniques for providing basic psychological support described in sections 7.4.2–7.4.5. → 7.4

**NOTE OF REFERRAL:** *If a depressive disorder is suspected, and if trained and supervised therapists are available, consider referring your patient for psychological therapy:* 

- cognitive behavioural therapy (CBT)
- interpersonal therapy
- problem-solving counselling
- behavioural activation.

#### Pharmacological treatment



Only consider antidepressants if:

- you have provided psychoeducation and psychological support as suggested but it has not helped;
- the more advanced psychological treatments listed above have failed or are unavailable; and
- you have been trained in their use or you can refer your patient to someone with such training.



# ASSESSMENT AND MANAGEMENT OF 7.5.2 ANXIETY DISORDERS

This section will show you how to recognize severe symptoms of anxiety that may be impairing functioning and also how to recognize some of the common anxiety disorders. Next, it describes the initial management that can be provided in all cases. It is intended to guide health workers in providing further assessment if indicated after implementing section 7.3, and more advanced care than was covered in section 7.4, if needed. ret 7.3 ret 7.4

# I. WHAT IS ANXIETY?

Anxiety disorders are a group of mental health disorders characterized by feelings of anxiety and fear, including generalized anxiety disorder (GAD), panic disorder, phobias, social anxiety disorder, obsessivecompulsive disorder (OCD) and post-traumatic stress disorder (PTSD). As with depression, symptoms can range from mild to severe (18).

Increased feelings of fear, worry, irritability, frustration, anxiety and obsessional symptoms as well as PTSD (see section 7.5.3) have all been reported in women who have undergone FGM (2,3,4,6).

#### **IMPORTANT!**



Worry, fear and anxiety are normal feelings that can occur in anyone in response to frightening or worrying events or situations. However, when such feelings are excessive, occur most of the time, or arise without an apparent trigger and interfere with daily activities/functioning, they may be part of an anxiety disorder. Anxiety disorders occur in women living with FGM for many of the same reasons as depression. Often both disorders coexist.



# II. ASSESSMENT FOR ANXIETY DISORDERS

Assess your patient starting with the questions in set A, then proceed to B and C as needed.



Have you experienced...

somatic (physical) complaints with no organic cause
(e.g. racing heart beat/palpitations, a feeling of suffocation,
dizziness, trembling/shaking, headaches, pins and needles [or the
sensation of ants crawling] on your limbs or face)?

- **negative feelings** (e.g. feeling as if something terrible is going to happen, constant fear)?
- negative thoughts (e.g. worrying too much about your problems/health; thinking that you are going to die, lose control or go mad; repeatedly thinking the same distressing thought despite efforts to stop)?
- **changed behaviour** (e.g. avoiding places or situations that make her anxious, avoiding socialising, poor sleep)?

# Daily functioning

*If the answer is "yes" to any of the symptoms listed in B,* then ask your patient:

How are you managing in your daily life...

- ... with your family and domestic activities?
- ... with your social activities?
- ... at work, school or other important areas of life?

If your patient answered "yes" to at least one question in A, and she has any of the symptoms listed in B, and if they are interfering with her life and preventing her from carrying out her normal activities (as indicated by her answers in C), she is probably suffering from severe anxiety symptoms or an anxiety disorder (see Box 7.4).

# BOX 7.4 What forms of anxiety disorders are there?

#### GENERALIZED ANXIETY DISORDER (GAD):

In many people, their anxiety is generalized, non-specific and without a focus. Often the person cannot pin their anxiety to particular fears or situations, but the general feeling of worry still severely affects their daily functioning.

#### SPECIFIC ANXIETY DISORDERS:

In other people, the anxiety takes a more specific form. There are three common forms of specific anxiety disorder.

# 1. Panic attacks

Sudden, overwhelming feelings of fear that something terrible is going to happen, associated with severe physical symptoms of anxiety (breathing much faster than usual due to fear leads to changes in the blood chemistry, causing physical symptoms). Panic attacks usually only last a few minutes, but they can result in avoidance and phobias about situations that might trigger them.

# 2. Phobias

Specific and exaggerated fears related to specific situations, such as crowded places, seeing blood, heights, or fears related to objects or animals such as spiders or snakes. A person with a phobia will go to great lengths to avoid exposure to that situation or object; in severe cases they may avoid leaving the house.

#### 3. Obsessive-compulsive disorders

Conditions where a person gets repeated thoughts (obsessions) or does things repeatedly (compulsions) even though the person knows these thoughts and actions are senseless or unnecessary.

The obsessions and compulsions can become so severe and frequent that they affect the person's concentration and normal functioning, and can lead to depression.



**NOTE OF REFERRAL:** In primary health care, the most important task with all three of the above anxiety disorders is to provide initial management (see subsection iv below, and section 7.4) and onward referral if needed and if available.  $\rightarrow$  7.4

#### **IMPORTANT!**



Symptoms of anxiety and depression often occur together. Women with either or both may present only with physical symptoms (e.g. chest pain, dizziness, aches and/or pains) and may be reluctant to discuss their thoughts and feelings due to embarrassment or fear. After you have excluded any organic cause for her physical symptoms (see section 7.6),  $\rightarrow$  7.6 it is important to explore further whether she is depressed or anxious.



# III. MANAGEMENT OF ANXIETY

Whether or not someone has an anxiety disorder, if their anxiety symptoms are causing high levels of distress (based on your assessment following the steps in the previous section), then consider the following management advice.

## Provide psychoeducation relevant to anxiety

Refer to section 7.4.1 for a basic description and outline of psychoeducation.  $\rightarrow$  74

For anxiety, include the following points in your explanation to your patient.

- Anxiety symptoms are very common. Fear and the bodily responses that accompany it – racing heart, fast breathing, etc. – can be very useful to help us deal with danger in some situations. Similarly, worrying can sometimes help with problem-solving and help us to avoid danger.
  - However, problems arise when these feelings and behaviours become overwhelming in situations where they are not needed. For example, one's heart may be beating fast despite being somewhere safe.

The body's response to fear is real. She is not imagining her physical symptoms. They are a result of the body's alarm system (see section 7.4.3). 27.4

Treatment involves learning to identify the situations and/or thoughts that trigger anxiety and using stressreduction techniques, particularly at those times (see section 7.4.3).  $\rightarrow$  7.4

#### **PRACTICE DAILY**

Practising those stressreduction techniques on a daily basis will also reduce anxiety.

Treatment takes time; usually it takes a few weeks before she will feel any positive effects.

6 Advise your patient that, even if it is difficult, she should try to do as many of the following as possible to help her feel less anxious.

- Continue to engage in activities that were previously pleasurable.
- Maintain regular sleeping and waking times.
- Be as physically active as possible.

Eat regularly despite changes in appetite.

Spend time with trusted friends and trusted family members.

Participate in community and other social activities as much as possible.

!

If she notices any thoughts of self-harm or suicide, she should not act on them. She should tell a trusted person and come back for help immediately (see Box 7.1 in section 7.3.2).

#### Support and assist your patient in reducing and coping with stress and strengthening her social support

Refer to the techniques for providing basic psychological support described in sections 7.4.2–7.4.5.  $\Rightarrow$  7.4

**NOTE OF REFERRAL:** If a severe anxiety disorder is suspected, and if trained and supervised therapists are available, consider referring your patient for psychological therapy, which has good results with these conditions:

- cognitive behavioural therapy (CBT)
- problem-solving counselling.

#### Pharmacology

DO NOT prescribe benzodiazepines or antidepressants for any anxiety disorder or acute distress. Guidelines for short-term use in exceptional cases of insomnia are provided in Box 7.5.

#### **REMEMBER:**

Psychoeducation is the main pillar of anxiety management. When your patient can understand the connection between her fears and her bodily responses, the anxiety around her physical symptoms is likely to diminish and allow her to explore the underlying fears.

# IV. MANAGEMENT OF SPECIFIC ANXIETY SYMPTOMS

#### **INSOMNIA AND HYPERVENTILATION**

If your client presents with the specific symptoms of insomnia or hyperventilation, regardless of whether there is a disorder or not, then consider the following points, respectively.

### Insomnia

- **Explain** that sleep problems (insomnia) are common when someone is anxious or stressed.
- **Explore and address** any environmental causes of insomnia (e.g. noise).
- 3

**Explore and address** any physical cause of insomnia (e.g. physical pain). **Advise** on sleep hygiene, including regular sleep routines (e.g. regular times for going to bed and waking up), and avoiding coffee, nicotine and alcohol late in the day or before going to bed. Emphasize that alcohol disturbs sleep.

If appropriate, advise against having any information and communication technology (ICT) devices (e.g. phone, computer) in the sleeping area. Explain that the light emitted by all such devices disturbs sleep.

## BOX 7.5 Use of benzodiazepines in exceptional cases of insomnia

Benzodiazepines may cause dependence. Use only for short-term treatment and in exceptional cases of insomnia. Benzodiazepines should not be used for any other symptoms of anxiety, depression, acute stress or PTSD.

In exceptional cases, in adults, when techniques for psychological support or stress-reduction are not feasible or effective for treating insomnia that severely interferes with daily functioning, short-term treatment (3–7 days) with benzodiazepines (e.g. diazepam 2–5 mg/day or lorazepam 0.5–2 mg/day) may be considered. In these cases, the following precautions should be taken.

- Check for drug-drug interactions before prescribing diazepam.
- Benzodiazepines can slow down breathing. Regular monitoring may be necessary.
- Monitor for side-effects frequently when using this medication in older people.
- DO NOT prescribe benzodiazepines to children or adolescents.
- Avoid this medication in women who are pregnant or breastfeeding.
- Benzodiazepines should not be used for insomnia caused by bereavement in adults or children.

**IMPORTANT!** This is a temporary solution for an extremely severe sleep problem. Common side-effects of benzodiazepines include drowsiness and muscle weakness.

# Hyperventilation as a symptom of panic disorder

- Rule out and manage other possible causes. Always conduct necessary medical investigations to identify possible physical causes, such as lung disease.
- If no physical cause is identified, reassure the person that hyperventilation (fast breathing) is part of the fight-or-flight response, which is triggered in a panic attack or when we are stressed, and that it is unlikely to be a serious medical problem.
- Be calm and remove potential sources of anxiety if possible (e.g. an over-anxious relative who is accompanying the patient). Help your patient regain normal breathing by using the slow breathing technique (see Box 7.3 in section 7.4.3), and teach her this method so that she can use it as needed. → 74
  - DO NOT recommend breathing into a paper bag.

ASSESSMENT AND MANAGEMENT OF 7.5.3 POST-TRAUMATIC STRESS DISORDER (PTSD)

> This section describes further mental health assessment and support for patients with symptoms and signs indicative of PTSD. It is intended to guide health workers in providing further assessment if indicated after implementing section 7.3, and more advanced care than was covered in section 7.4, if needed.  $\Rightarrow$  7.3  $\Rightarrow$  7.4

# I. WHAT IS PTSD?

PTSD is an anxiety disorder that can occur when a person who has lived through a terrifying, painful and upsetting experience finds himor herself reliving that event repeatedly in their mind in the form of nightmares or flashbacks. Because these are unpleasant experiences, the person may also avoid any situations or places that trigger memories of the event, and at the same time they may be constantly alert to any hint of danger or risk that the event might happen again. It is quite normal to feel and behave this way in the immediate weeks after an upsetting event. However, when this persists for more than a month and interferes with the person's normal ability to function, it is likely that the person has PTSD, or symptoms of PTSD, as for example in this case vignette.

# CASE VIGNETTE 2

WOMAN: "My family doctor is a man, and I don't feel like showing him my private parts. That means having to explain everything all over again, and that is something I absolutely don't feel like. I don't want to be reminded of the pain."

INTERVIEWER: "What does the pain do to you?"

WOMAN: "I start to tremble all over, and all the memories come flooding back. I cannot do anything for the next few days, and all I want to do is sleep."

- 35-year-old Somali woman living in the Netherlands (14)



# II. ASSESSMENT FOR PTSD

Women who have suffered traumatic experiences may not present with specific PTSD symptoms. They may initially complain of more non-specific problems, such as:

- sleep problems (e.g. lack of sleep);
- irritability, persistent anxious or depressed mood; and
- multiple persistent somatic complaints with no organic cause (e.g. headaches, pounding heart) (see section 6.6). → 6.6

Women who present at a health-care facility with these difficulties should always be questioned further to see if the characteristic PTSD symptoms listed below are present. Some women may present directly with one or more of these symptoms listed below.

# Core symptoms of PTSD

To make a diagnosis of PTSD, all three must be present.

1

#### Re-experiencing symptoms

The patient has repeated and unwanted recollections of a traumatic experience as though it is occurring in the here-and-now (e.g. frightening dreams, flashbacks or intrusive memories of the event, accompanied by intense fear or horror).

#### 2 Avoidance symptoms

The patient deliberately avoids thoughts, memories, activities or situations that remind her of the traumatic event (e.g. avoiding talking about the event or going back to the place where the event happened). 3

Symptoms related to a heightened sense of current threat The patient is excessively concerned and alert to danger or reacts strongly to unexpected sudden movements (e.g. being "jumpy" or "on edge").

If these symptoms occur in the first few weeks after a traumatic event such as FGM, this may be part of the normal response to traumatic events. It is not a disorder but an acute stress reaction and can be helped by the techniques for providing basic psychological support described in section 7.4.  $\rightarrow$  7.4



**IMPORTANT!** If these three symptoms have persisted for more than a month after the traumatic event and are combined with difficulties in day-to-day functioning, then the patient has PTSD.

Example exploratory questions could include:

Some young women who have had a similar experience to you find that they dream about it. Has this happened to you?

In some situations, they feel as if the event is happening again. Has this happened to you?

Do you find yourself avoiding situations or conversations that remind you of what happened?

Do you find you feel jumpier or more alert than seems normal?

#### **IMPORTANT!**

For women with FGM, presence of any of the following risk factors means it is particularly important to conduct further assessment for PTSD.

- The woman has undergone type III FGM (infibulation).
- She has clear memories of the cutting.
- No anaesthetic was used during the procedure.
- She has physical health complaints associated with the FGM.
- She has received information about FGM and the associated risks (particularly in migrant communities).
- FGM took place at an older age (14). 1

<sup>1</sup> The last two points in this list are not intended to imply that FGM should be carried out at a younger age, or that there should not be information campaigns against FGM. It does suggest a greater need for care and sensitivity in dealing with these issues.

#### PTSD AND OTHER MENTAL HEALTH DISORDERS CAN COEXIST

Always check to see if your patient also suffers from depression (see section 7.5.1) or anxiety (see section 7.5.2).

Check if there is suicidal thinking or any problem of drug or alcohol use and abuse (see Box 7.1 in section 7.3, and refer to relevant sections in the *mhGAP intervention guide, version 2.0,* for guidance on management; see details in the bibliography at the end of the chapter). 273

Some women may have one or two persistent post-traumatic symptoms, such as flashbacks and avoidance, without having the full disorder (i.e. the three core symptoms and difficulties in daily functioning for more than a month). These patients will still benefit from the management suggestions on the following page.



# III. MANAGEMENT OF PTSD

If, after completing the steps in the previous section, you conclude that your patient is suffering from PTSD, then consider the following four points.

### Provide psychoeducation relevant to anxiety

Refer to section 7.4.1 for a basic description and outline of psychoeducation.  $\rightarrow$  74

For PTSD, include the following points in your explanation to your patient.

- 1 Many people recover from PTSD over time without treatment. However, treatment will speed up recovery.
  - People with PTSD often feel that they are still in danger, and may feel very tense. They are easily startled ("jumpy") or constantly on alert for danger.
- People with PTSD repeatedly experience unwanted recollections of the traumatic event. When this happens, they may experience emotions such as fear and horror similar to the feelings they had when the event was actually happening. They may also have frightening dreams.
  - People with PTSD try to avoid any reminders of the event. This is because reminders can trigger flashbacks and the accompanying

feelings of fear and horror. In the case of FGM, this might include avoiding sexual intercourse, pregnancy or any surgical interventions. Such avoidance can cause problems in women's lives. Treatment can help.

- Paradoxically, trying to avoid thinking about something usually results in thinking about it more.
- If appropriate, explain that people with PTSD may have other physical and mental problems, such as aches and pains in the body, low energy, fatigue, irritability and depressed mood.
- Advise your patient that, even if it is difficult, she should try to do as many of the following as possible.
- Continue normal daily routines as far as possible.
- Maintain regular sleeping and waking times.
- Be as physically active as possible.
- Talk to trusted people about how she feels or what happened, but only when she is ready to do so.
  - Engage in relaxing activities to reduce anxiety and tension.
- ✓ Avoid using alcohol or drugs to cope with PTSD symptoms.

7

If she notices any thoughts of self-harm or suicide, she should not act on them. She should tell a trusted person and come back for help immediately (see Box 7.1 in section 7.3.2). 7.3

## Support and assist your patient in reducing and coping with stress and strengthening her social support

Refer to the techniques for providing basic psychological support described in sections 7.4.2–7.4.5.  $\bigcirc$  7.4

**NOTE OF REFERRAL:** *If PTSD is suspected, and if trained and supervised therapists are available, consider referring your patient for psychological therapy:* 

- individual or group cognitive behavioural therapy with a trauma focus (CBT-T);
- eye movement desensitization and reprocessing (EMDR).

#### Consult a mental health specialist (if available)

If there is no one who is trained to deliver either CBT or EMDR **or** she is at imminent risk of suicide/self-harm, consult a mental health specialist.

**NOTE ON FOLLOW-UP:** Schedule a second appointment within two to four weeks, and later appointments depending on the course of the disorder.

#### WHO RECOMMENDATION

Cognitive behavioural therapy (CBT) should be considered for girls and women living with FGM who are experiencing symptoms consistent with anxiety disorders, depression or post-traumatic stress disorder (PTSD) (12).

#### CBT may be considered if:

- a psychiatric diagnosis of anxiety disorder, depression or PTSD has been established, and
- there is a competent (i.e. trained and supervised) provider available to deliver it.

# ASSESSMENT AND MANAGEMENT OF 7.6 OTHER MENTAL HEALTH PROBLEMS

Many women affected by FGM may suffer from particular symptoms involving their emotions (e.g. depressed mood, anxiety, irritability), thoughts (e.g. ruminating, poor concentration) or behaviour (e.g. inactivity, withdrawal, isolation, avoidance), but still continue to be able to function day to day, carrying out their normal activities. Some of these women, however, may present with somatic symptoms, such as chronic pain, that do not have any known physical/ organic cause. These symptoms may indicate a less severe emotional disorder (e.g. mild forms of depression, anxiety or post-traumatic stress disorder [PTSD]) or they may represent normal distress (i.e. no disorder).



# 7.6.1 ASSESSMENT FOR OTHER MENTAL HEALTH PROBLEMS

It is essential to take the following two steps before proceeding to manage the patient's symptoms.

- Exclude more severe disorders by following all the guidance on mental health assessment provided in section 7.5 of this chapter.  $\rightarrow$  7.5
  - Exclude organic causes such as heart disease or arthritic conditions by conducting a full physical examination.



# 7.6.2 MANAGEMENT OF MENTAL DISTRESS AND SOMATIC COMPLAINTS WITH NO ORGANIC CAUSE

DO NOT prescribe anti-anxiety or antidepressant medicines (unless advised by a specialist).

**DO NOT** give vitamin injections or other ineffective treatments.

In all cases, reduce stress and strengthen social support. Follow the guidance in section 7.4.  $\bigcirc$  7.4

In particular be sure to:

- reduce current psychosocial stressors (section 7.4.2)
- teach and encourage the use of stress-reduction techniques (section 7.4.3)
- strengthen social support (section 7.4.5).

# Manage your patient's expectations, provide possible explanations and offer support

Take the following steps.

**Inform** your patient that no physical condition or serious disease has been identified that fully explains the presenting somatic symptom(s). **Communicate** the normal clinical and test findings. Avoid ordering more laboratory tests or other investigations unless there is a clear medical indication, e.g. abnormal vital signs. If a further test/investigation has been ordered, reduce unrealistic expectations by telling your patient that the result is likely to be normal.

**If your patient insists on further investigations**, consider saying that performing unnecessary investigations can be harmful because they can cause unnecessary worry and side-effects.

Let her know that you acknowledge that the symptoms are real and not imaginary, and that it is still important to address symptoms that cause significant distress.

Ask the girl or woman for her own explanation of the cause of her symptoms, and ask about her concerns. This may give you clues about the source of her distress, help build a trusting relationship between you, and increase her adherence to treatment.

**Explain** that emotional suffering/stress often involves the experience of bodily sensations, such as stomach aches and muscle tension. Ask for and discuss potential links between her emotions/stress and symptoms.

**Encourage** positive comping and continuation of (or gradual return to) daily activities (see sections 7.4.4 and 7.4.6).  $\rightarrow$  7.4

**Remember** to help her to reduce stress and strengthen social support (see sections 7.4.2, 7.4.3, 7.4.5).  $\bigcirc$  74



# 7.6.3 MANAGEMENT OF ACUTE STRESS IN PATIENTS PRESENTING WITH SOMATIC SYMPTOMS

If the girl or woman is presenting shortly after experiencing FGM, or is presenting with secondary complications due to FGM, or if she has recently undergone treatment for FGM that has been distressing or upsetting, her somatic symptoms may be a manifestation of acute stress. In such cases, in addition to the points in section 7.6.2 above, also do the following.

X DO NOT pressure the girl or woman to talk about what happened. emotions/stress and symptoms.

## Explain the following points to her.

- People often have reactions after traumatic or distressing events. Th e reactions may be highly variable from person to person and may change over time.
- Reactions to such events can include somatic symptoms such as palpitations, headaches, other aches and pains, gastric upset, and emotional and behavioural symptoms such as sleep disturbance, sadness, anxiety, irritation and aggression.


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#### Chapter 7 | Mental health & FGM



# SEXUAL HEALTH & FGM

# After reading this chapter you should be able to:

- Understand what sexual health and sexuality are
- Understand the importance of providing sexual health care and support for women living with FGM
- Understand the female sexual response, and the anatomical structures involved in it
- Recognize the factors that influence the sexual well-being of women
- Recognize the sexual health consequences of FGM
- Perform a first-line assessment of the sexual health and well-being of women living with FGM
- Enquire about and discuss sexual health with your female patients who are living with FGM
- Offer first-line sexual health care and support to women living with FGM
- Understand when women who have undergone FGM should be offered vulvar surgery and clitoral reconstruction

### In this chapter



#### 8.1 UNDERSTANDING SEXUAL HEALTH



# 8.1 UNDERSTANDING SEXUAL HEALTH

Sexual health can be defined as "a state of physical, emotional, mental and social well-being in relation to sexuality" (1). The definition also states that in order to enjoy a healthy sexual life the absence of disease or disability is not enough. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of pressure, discrimination and violence (1).

### WHY IS SEXUAL HEALTH IMPORTANT?

Sexual health is important for the following reasons.

- All women and men have the right to fulfil and express their sexuality and enjoy sexual health (2).
- A person's sexual functioning is closely linked to their quality of life; they can influence each other in a positive or a negative way (3).
- Sexual activity is intimately linked to attachment: certain hormones released during sexual activity promote a strong bond between sexual partners (4).
- Experiencing feelings of love and desire, and engaging in sexual intercourse, can reduce stress in women and men (5).

In the case of women living with FGM, they have experienced a practice that damages anatomical structures that are directly involved in the female sexual response. This can affect a woman's sexual health and well-being *(6)*.

# NOT ALL WOMEN WHO HAVE UNDERGONE FGM WILL EXPERIENCE SEXUAL HEALTH PROBLEMS.

However, health-care providers should be aware of the risks and potential problems so that they can appropriately address the healthcare needs of this population, including sexual health.

# 8.2 THE FEMALE SEXUAL RESPONSE

Sexuality is an important aspect of being human (1). Our sexuality is characterized by how we feel, think or act in a sexual way (7). It reflects an interaction of several elements, including the sex, gender identities and roles, and sexual orientation of a person; their particular sense of eroticism, pleasure and intimacy; and reproduction (1).

Human beings experience and express sexuality in different ways, such as when they think about a sexual situation, or when a woman and her husband embrace, kiss and share other expressions of love. Sexuality can be influenced by several factors (see table 8.1 in section 8.4) (1).  $\Rightarrow$  8.4

### DESCRIBING THE FEMALE SEXUAL RESPONSE

The female sexual response is a series of changes that take place in a woman's brain and body during sexual arousal and activity (8,9).

It was initially described using a linear model that included four phases: sexual desire, sexual arousal, orgasm and resolution (8) (see Box 8.1). This model has evolved in more recent years to incorporate the idea that not all women experience all four of those phases. For example, a woman may not experience sexual desire but she may still choose to engage in sexual activity to experience emotional closeness with her husband or partner, or she may experience desire and arousal, and may feel sexual satisfaction but not orgasm.

More recent models of the female sexual response take into consideration that female sexuality is the integration of biological and psychological factors. These include: attraction, sexual stimuli, arousal, sexual pleasure, and a sense of physical, emotional and relational satisfaction (10).

More importantly, for a woman to perceive her sexual response, she must know how to "listen" to her body (4). And for her biological responses to be perceived as pleasant, a woman needs to have positive emotions and thoughts about the sexual encounter (4). Finally, to allow these biological responses to turn into pleasant excitement, a woman needs sufficient time to enjoy them; each woman has her own tempo.

### BOX 8.1

## GLOSSARY OF ADDITIONAL SEXUAL HEALTH TERMS

The following terms are frequently used when discussing sexual health.

**Sex:** The biological characteristics that define humans as female or male. In general use in many languages, the term "sex" is often used to mean "sexual activity", but in the context of sexuality and sexual health discussions, the above definition is preferred (1).

**Sexual desire/eroticism:** A state or feeling of inclination towards sexual intimacy.

**Sexual arousal:** A state of sexual responsiveness to stimulation of the senses (sight, smell, hearing, taste or touch).

**Pleasure:** A positive sense of enjoyment or satisfaction (physical and/or psychological).

**Intimacy:** A close emotional and/or physical relationship with oneself or another person.

**Orgasm:** The climax of sexual excitement.

8.2

## **REMEMBER:**

All women and men have the right to fulfil and express their sexuality and enjoy sexual health (2).

# 8.3 ANATOMICAL STRUCTURES INVOLVED IN THE FEMALE SEXUAL RESPONSE

The female sexual response involves multiple parts of the body and brain. For example, during sexual arousal, a woman's heart rate and blood pressure start climbing and the blood supply to the genital organs increases. A number of the changes involved in the female sexual response occur in the genital area, specifically the vulva. The female vulva comprises several anatomical structures that are involved in the female sexual response. One or several of these structures may be harmed by FGM. The anatomical structures that are involved in the female sexual response and which are potentially affected by FGM are described on the following pages.



Figure 8.1 Anatomical structures of the female vulva

*Labia majora:* The labia majora undergo congestion during sexual arousal, which leads to an increase in local sensitivity.

*Labia minora:* These fine folds of skin, rich in nerve endings and blood vessels, also undergo significant swelling during sexual arousal, leading to increased sensitivity.

*Orifice of the urethra:* During sexual excitement, the sensitivity of this structure increases due to the congestion of the surrounding tissues.

*Vagina and vaginal opening:* The vagina is an extendible, channel-like organ. Women can, voluntarily and involuntarily, contract their perineal muscles and relax or tighten the vaginal opening during sexual intimacy.

*Clitoris:* The clitoris is a boomerang-shaped organ located below the pubic symphysis. Its function is to provide sexual pleasure to the woman. Anatomically, the clitoris has both external and internal structures.

• The external (visible) part of the clitoris – the clitoral glans – is covered partially or totally by the clitoral hood and the anterior fold of the labia minora. The clitoral glans contains erectile tissue and is full of free nerve endings (twice as many as there are in the male glans). During sexual arousal, the clitoral glans engorges and its sensitivity increases.



Figure 8.2 Anatomical structure of the clitoris

8.3

• The internal part of the clitoris is composed of the "body" and the "crura" and is located inside the woman's body. The crura consist of erectile tissue. In contact with the crura are the vestibular bulbs; the crura and the bulbs surround both sides of the vaginal opening (see Figure 8.2). During sexual arousal, the crura and the bulbs also swell and increase their sensitivity.



**IMPORTANT!** FGM only affects the external (visible) part of the clitoris – the clitoral glans. The crura and part of the body of the clitoris remain intact under the scar. Their sexual function also remains intact (11).



*Figure 8.3* Anatomical structure of the clitoris in profile view

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8.3

8.4 FACTORS THAT INFLUENCE THE SEXUAL WELL-BEING OF WOMEN

### FOUR CATEGORIES OF FACTORS

Women's sexual well-being is influenced by many factors. These factors can be grouped into four categories.



Table 8.1 on the next page summarizes these factors. As a healthcare provider, it is very important to have these factors in mind while taking a sexual health history.

# TABLE 8.1Factors that influence sexual health and well-being

### **BIOLOGICAL FACTORS (12)**

*Factor* (and examples)

#### SYSTEMIC DISEASES

- Any systemic infection (e.g. flu, gastroenteritis)
- Chronic diseases (e.g. diabetes)

#### LOCAL DISEASES

- Reproductive tract infections
- Vulvar abscess
- Clitoral neuroma

#### **GENITAL INJURIES**

- Perineal tears after childbirth
- FGM

#### **BODY INJURIES**

- Bone fractures
- Recovery after a surgical procedure

Effect o<mark>n female</mark> sexual health

When a woman is sick and feels unwell, she is less likely to feel interested in sexual intercourse.

Local diseases in the genital area can lead to pain and discomfort in this area.

The genital injury or scar can cause pain and discomfort during sexual intercourse.

If a woman has been injured and is feeling pain somewhere else in her body, she is less likely to experience sexual desire, arousal and orgasm.



Antidepressants

### NATURAL HORMONAL VARIATIONS

- Breastfeeding
- Menopause

Antidepressants can alter sexual desire or arousal.

Women who are breastfeeding or have entered menopause sometimes have less sexual desire and may suffer from vaginal dryness.

### **HORMONAL CONTRACEPTIVES**

• Birth control pills, injections or implants

Some women may experience reduced sexual desire when using hormonal contraceptive methods.

### INTERPERSONAL FACTORS

### Factor

(and examples)

### MARITAL OR RELATIONSHIP PROBLEMS

- Difficult marriage
- Forced marriage

# Effect on female sexual health

Current or previous marital or relationship problems can have a negative impact on sexual experiences. This often causes sexual dissatisfaction.

### TABLE 8.1 CONTINUED...

### PSYCHOLOGICAL FACTORS (6,9,13,14,15)

#### Factor

(and examples)

### HARMFUL PERSONAL BELIEFS RELATED TO SEXUALITY

- "Sexual intercourse is dirty"
- "Women with FGM cannot enjoy sex"

#### **NEGATIVE BODY IMAGE**

- Disliking particular body parts/features
- Feelings of being "incomplete" in women living with FGM

### MENTAL HEALTH PROBLEMS AND DISORDERS

- Depression, anxiety
- Low self-esteem

#### STRESSFUL LIFE EVENTS

- Financial problems
- Disagreements with family or community

### PAST TRAUMATIC EXPERIENCES

(whether or not they are linked with FGM)

- Sexual violence
- The event of FGM

# Effect on female sexual health

Personal beliefs can have a powerful influence on the way a woman perceives sexuality and may interfere with her ability to enjoy sexual intercourse.

These negative feelings can damage a woman's self-image, which can damage her relationship with her husband or partner.

When a woman feels psychologically unwell she is less likely to feel interested in sexual intercourse.

Worries can prevent women from enjoying sexual intercourse.

The pain and fear felt during previous traumatic events can sometimes be reactivated when sexual intimacy is initiated or even proposed.



#### Factor

(and examples)

### HARMFUL SOCIOCULTURAL PRACTICES AND BELIEFS ABOUT SEXUALITY

- "Male sexual pleasure is more important than female sexual pleasure"
- "Sex is more pleasurable for men if a woman is 'dry'"

# Effect on female sexual health

Some sociocultural beliefs do not value female sexual pleasure, making it difficult for a woman to enjoy sexual intercourse openly, while certain practices can be harmful for a woman's health and cause discomfort and pain during sexual intercourse.

8.

# 8.5 SEXUAL HEALTH CONSEQUENCES OF FGM

Evidence shows that compared to women without FGM, women who have undergone genital cutting are more likely to experience:

- dyspareunia (pain during sexual intercourse)
- reduced sexual satisfaction
- reduced sexual desire (6).

## HOW CAN FGM AFFECT THE SEXUAL HEALTH OF WOMEN WHO HAVE UNDERGONE THE PROCEDURE?

FGM involves the removal of sexually sensitive tissues, such as the external portion of the clitoris, the labia minora and/or the labia majora. This can reduce sexual sensation in some women. Pain during sexual intercourse may occur with different types of FGM as a result of vaginal narrowing and infibulation (type III FGM), painful scar tissue or post-traumatic clitoral neuroma. Moreover, if a woman feels pain during her sexual encounters, she is likely to feel anxious and stressed each time she experiences or anticipates sexual intimacy.

### **IMPORTANT!**



The female genitalia are not the only determinants of female sexual response. The sexual well-being of women living with FGM, like other women, is influenced by a complex interaction of biological, psychological, sociocultural and interpersonal factors, as described in Table 8.1. It would be a mistake to assume that all sexual health problems in this population relate to genital cutting. In the case of women living with FGM, the following factors may also influence their sexual health and well-being.



### **REPEATED NEGATIVE SEXUAL EXPERIENCES**

If a woman has repeatedly experienced pain or no sexual pleasure during sexual intercourse, she may consider that this is normal or that it is not possible to improve her sexual experiences.

### PERSONAL BELIEFS LINKED TO SEXUALITY

Sexuality is often influenced by beliefs that are rooted in personal and sociocultural factors. These beliefs can have a powerful influence on the way a person perceives sexuality and they can sometimes prevent a woman from enjoying sexual intercourse.



Box 8.2 lists the most common false beliefs about female sexuality.



### PREVIOUS TRAUMATIC EVENTS

Any act of forced sexual intercourse or the event of FGM itself can be very traumatic for a woman. The pain and fear felt during these traumatic events can sometimes be reactivated when sexual intimacy is initiated or even proposed *(18)*.

### **NEGATIVE EMOTIONS IN CONNECTION TO FGM**

Some women who have undergone FGM develop negative emotions towards the procedure and negative body image in relation to their own genitalia. In these cases, the woman may feel uncomfortable if her husband or partner sees her genital organs; she may feel ashamed of having undergone FGM.





### MARITAL LIFE/RELATIONSHIP PROBLEMS IN CONNECTION TO FGM

Sometimes, sexual health difficulties linked to FGM can prevent couples from developing a healthy and fulfilling sexual life (e.g. chronic sexual pain, refusal to engage in sexual intercourse, fear of intimacy, anger). This can cause great frustration and sadness in one or both partners and may damage the couple's relationship.

### BOX 8.2 Examples of false beliefs about female sexuality





8.



Yes, they can. Women living with FGM who experience sexual health difficulties can learn the information and skills needed to reach a satisfying and pleasurable sexual life with the help of sexual health education and support services.

### **KEY FACTS:**

- An intact external clitoris is not the only determinant of female sexual well-being or pleasure.
- A large portion of the clitoris is not excised during FGM and remains beneath the scar tissue. Other structures involved in the female sexual response may also remain intact. Therefore, even if the external clitoris has been excised, with adequate sexual health care and support, women living with FGM can experience satisfying sexual relationships and achieve orgasm (11).
- Emotional, psychological, sociocultural and interpersonal factors also play an important role in sexual well-being and can be improved with adequate sexual health care and support (19).

- Some studies among women living with FGM have found that they report experiencing orgasm and sexual pleasure (14,20).
- With a good interpersonal relationship and open communication, couples can learn to have satisfying sexual relationships despite FGM.

# 8.6 ADDRESSING THE SEXUAL HEALTH & WELL-BEING OF WOMEN LIVING WITH FGM

Many health-care providers say that they don't initiate conversations on sexual health or sexuality issues because they lack the essential skills to address these concerns. But communication about sexual health between providers and patients has been found to have a positive impact on women's sexual health (21,22).
## 7

# Why should health-care providers discuss sexual health and sexuality with women living with FGM?

Sexual expression is a normal and healthy part of human behaviour. However, many health-care providers do not feel prepared to speak with their patients about sexual health and sexuality because of the sensitive nature of the topic and/or their lack of relevant training. Health-care providers should enquire about sexual health and sexuality for the following reasons.

Sexuality is a natural part of human experience and behaviour (1).

A healthy sexual life is not only the absence of disease or disability. Sexual health also requires a positive and respectful approach to sexuality, as well as the possibility of having pleasurable and safe sexual experiences (1).

Women often find it difficult or shameful to talk or ask spontaneously about sexual health difficulties. Some may think that speaking about sex is "not decent" or something "only prostitutes do". These beliefs lead them to keep silent.

Research findings indicate that women generally welcome the opportunity to discuss sexual health when a health-care provider opens the conversation in the context of a health-care consultation (21,23).

Communication between health-care providers and patients has been shown to improve the sexual well-being of women (21,22,24).

Many women accept their sexual difficulties as "normal" when other women in the community have said that they also experience them.

Not all women have access to sexual health education and information.

Some women living with FGM believe that genital cutting deprives them of any access to sexual pleasure and therefore they have never explored or developed the capacities of their bodies to achieve pleasurable sensations (25).

In recent years, the Internet has become an easily accessible source of information on sex and sexuality. Unfortunately, a large portion of the available information is unrealistic and often degrading towards women (i.e. pornography) (26).

For all these reasons, health-care providers have an important role to play in educating women about sexual health and providing correct information and positive messages (26).

## CULTURAL NOTE 💭

In some cultures, it may be difficult or excessively uncomfortable – for both parties – if a male health-care provider discusses sexual health concerns with a female patient. In these cases, referral to a female health-care provider may be an appropriate option, if available.

## Can non-specialist health-care professionals provide sexual health support and care to women living with FGM?

As a health-care provider who is not specialized in providing sexual health care, you are not expected to provide in-depth sexual therapy. Your role is primarily to listen and enquire about the patient's sexual health concerns and offer first-line support and care by providing essential information and helpful suggestions (27,28,29). The most important skills to master include listening, asking questions, showing empathy and responding constructively to specific problems, which are all part of the basic counselling skills required for health-care providers to support women to find solutions to their problems.

If you open up a conversation on the topic, your patient is likely to feel empowered and supported to share her experiences. You can then reassure her that despite the fact that FGM can indeed affect her sexual health, you can help her find solutions and support her to improve her sexual well-being. Section 8.7 will equip you with the basic information and skills required to do this.  $\bigcirc$  8.7

## 8.6.1 GENERAL CONSIDERATIONS FOR PROVIDERS WHEN DISCUSSING SEXUAL HEALTH WITH PATIENTS

The following are some general principles you should adhere to when discussing sexual health with your patients.

Approach the consultation with a **positive attitude**; this will help your patient feel comfortable and at ease.

Always **respect the woman's views** during the conversation and maintain a non-judgemental approach; sexuality is subject to individual and cultural variations (25).

Avoid the use of words that may seem judgemental, such as "why", when asking questions. For instance, instead of asking "Why are you not interested in sexual intimacy?", ask "What are some of the reasons that make you feel less interested in having sexual intimacy with your husband/partner?"

It is normal for a woman to be reserved, embarrassed, suspicious and even stressed when discussing her sexual health. You can **encourage trust** by assuring confidentiality by ensuring privacy and by assuring her that the discussion is confidential. For example, you can say:

I know that it is not easy to talk about such an intimate subject, but everything we discuss will remain confidential. Be patient and respect the woman's ability to express herself and share information about her intimate life on her own terms and in her own words.

**DO NOT** pressure her.

Assist your patients to find their own solutions. Their own wishes should determine the care plan. It is important that you respect their decisions and do not pressure them.

## **8.6.3 ETHICAL CONSIDERATIONS**

#### **NOTE OF REFERRAL**

- Providers have a duty to refer patients to another health-care provider if they feel that their own moral, ethical or professional limitations are being exceeded.
- In case of reports of non-consensual sex, or sexual violence, explain that this is a violation of a person's rights and that no one deserves to be treated this way. Provide referrals where possible.



**IMPORTANT!** A spouse or partner should only participate in a health-care consultation session on sexual health if it is in the patient's therapeutic interest and only with the patient's consent.

ASSESSING THE 8.7 SEXUAL HEALTH & WELL-BEING OF WOMEN LIVING WITH FGM



## 8.7.1 OPENING THE CONVERSATION

This step involves "breaking the ice" by inviting the patient to feel comfortable talking about the topic of sexual health and sexuality.



Including a question about these topics during routine historytaking will help you identify women who may be experiencing sexual health difficulties. This can be done during any health-care consultation with your patient, whether it is your first or a subsequent contact with her.

Include the question among other routine questions, not in isolation and not as the first question during a consultation.

**Be mindful of your choice of words and your body language** while asking about sexual experiences and sexual health. It should be clear to your patient that you are comfortable discussing the topic and that you are not embarrassed; this will help to put her at ease.

**Providing some reading materials on sexual health, especially in relation to FGM** (e.g. brochures or leaflets placed in a strategic place in the consultation room as well as in the waiting area) can sometimes help women ask about any potential sexual health concerns.





Begin by assuring your patient that asking these questions is a routine part of health care.

For example you could say:

I ask all my patients about their sexual health as this is part of their general health; is it all right if I ask you a few questions?

> I am aware that some women living with FGM may experience some sexual health difficulties; do you have any sexual concerns that you would like to talk about?

Are you and your partner experiencing any sexual difficulties?

**Ask follow-up questions** to probe further about any sexual difficulties, as appropriate.

If you do not fully understand the terms your patient is using to refer to sexual health issues, it is best to clarify what she means instead of making assumptions.



## 8.7.2 DISCUSSING FURTHER DETAILS

If your patient tells you that she has sexual health concerns or is experiencing sexual health difficulties, you can proceed to take a brief sexual health history. Be sure to ask about the following issues.

### ENSURE SUFFICIENT TIME

Discussing sexuality-related issues should not be rushed. Sometimes several consultations will be necessary. Make sure you have enough time to explain things carefully and answer any questions the woman may have.



Ask about medical, sociocultural, psychological and interpersonal factors that may be influencing your patient's sexual health and well-being

- Use Table 8.1 to guide your discussion and basic assessment.
- It may be appropriate to recommend a focused medical exam and laboratory tests to determine the cause of the problem, if a biological cause is suspected.

## Ask about details specific to FGM

Establish what type of FGM your patient has. Ask your patient if she knows the extent of the cutting. For more information on how to ask about FGM, see Chapter 2.

**Determine** whether your patient has any health conditions possibly related to FGM that could have an impact on sexual functioning (e.g. scar tissue, cysts or keloids in the genital area, genital tract infections). When asking about health conditions possibly related to FGM, you can use drawings of the different types of FGM and anatomical structures (see Figures 8.1, 8.2 and 8.3/Job aids I and V).

## Enquire & reassure...

If needed, explain to her that a genital examination could help you determine the type of FGM she has and diagnose any conditions that could be causing her sexual health difficulties. For more details on how to perform a genital examination, see Chapters 3 and 4.

Use the drawings again after the external genital examination to explain what you found.

## Discuss intimate hygiene practices...

These practices are often not covered during history-taking despite the fact that they can have a significant impact on women's sexual health.

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Ask the woman how often she cleans her genital area; what products she uses; and if she uses any products to make her genital area "drier" (such as herbs, chalk, bleach or corrosive products to prevent lubrication and keep the vagina "tighter" for the pleasure of her husband or partner). For example, you can say:

I would like to ask you some questions about your personal hygiene.

How often do you wash your intimate parts?

What products do you use on your genital area and why?

For more information on correct vulvar hygiene, see section 5.3.1 in Chapter 5.

## Ask about personal beliefs about sexuality ...

Respectfully ask the woman about her beliefs in relation to sexuality. You could ask her:

What are your thoughts on sexuality?

What does your community say about it?

What does your partner say about it?

Have you ever had a talk about sexuality as a couple, and/or with a family member?

**IMPORTANT!** Do not judge your patient's personal beliefs about sexuality, even if they are incorrect. Instead, you can take the opportunity to provide factual information, clarify misinformation and answer any questions your patient may have.

If you have verified that your patient is experiencing sexual health difficulties, you will need to proceed to a management phase (see section 8.8).



8.8 FIRST-LINE SEXUAL HEALTH SUPPORT & CARE FOR WOMEN LIVING WITH FGM If you have determined that your patient has sexual health concerns or is experiencing sexual health difficulties, below are four simple steps that you can take to help improve her sexual health and wellbeing – even if you are not a specialist in sexual health.

- 8.8.1 Manage health conditions that may affect your patient's sexual health and well-being
- 8.8.2 Provide essential information on sexual health and sexuality
- 8.8.3 Enquire about her relationship with her husband or partner
- 8.8.4 Promote positive ideas about sexuality



## 8.8.1 MANAGE HEALTH CONDITIONS THAT MAY AFFECT YOUR PATIENT'S SEXUAL HEALTH AND WELL-BEING

If during the consultation and genital examination you identify conditions that cause obstruction of the vaginal opening, or that could cause pain and sexual discomfort, manage these as appropriate or ask the woman to return for further care.

Such conditions may include:

- infibulation in women with type III FGM (for more details on how to provide counselling for deinfibulation, see Chapter 6); → 6
- painful or obstructive cysts and keloids in the genital area;
- vulvar adhesions;
- clitoral neuroma;
- vulvar abscess; and
- reproductive or urinary tract infections.

You can find information on how to manage these conditions in Chapters 4 and 5 in this handbook.  $\rightarrow$  4  $\rightarrow$  5

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**NOTE OF REFERRAL:** *If necessary, refer her for further management.* 

## 8.8.2 PROVIDE ESSENTIAL INFORMATION ON SEXUAL HEALTH AND SEXUALITY

Women living with FGM sometimes do not know the exact physical impact of FGM on their bodies or the type of FGM they have undergone. They may also have certain beliefs or misinformation about sexuality that prevent them from enjoying the sexual side of their relationship with their husband or partner. Providing women with essential information about sexual health and sexuality, including about their anatomy and the female sexual response, and helping them to feel empowered to talk with their husband or partner about sexuality, can contribute substantially to improvements in women's sexual health and well-being.

Invite your patient to discuss these subjects as described on the following pages.

## SOME TOOLS THAT MAY BE USEFUL DURING THE CONSULTATION:

- Drawings of the types of FGM (Job aid I)
- Step-by-step drawings of the deinfibulation procedure (Job aid III)
- Drawings of the full clitoris (external and internal parts) (Job aid IV)
- A mirror

#### ANATOMY AND THE FEMALE SEXUAL RESPONSE IN WOMEN LIVING WITH FGM

1 Start the conversation by acknowledging the potential impact of FGM on the woman's sexual response (since genital cutting affects sexually sensitive genital tissues).

In order for trust to develop between a woman and her healthcare provider, it is important to put her at ease, avoid being judgemental and ensure privacy and confidentiality.

- With the help of images (Figures 8.1, 8.2 and 8.3 or Job Aid V), explain to her which anatomical structures are involved in the female sexual response and their function (refer to the information in section 8.2 and 8.3).  $\rightarrow$  8.2  $\rightarrow$  8.3
  - Based on the results of the genital examination, **show** your patient a diagram of the type of FGM she has undergone, and **explain** which genital structures were excised or altered.
    - **Show** her an image of the clitoris (Figures 8.2 and 8.3) and **explain** that her internal clitoris is still under the scar tissue and that it has the potential of giving her sexual pleasure.
    - **Remind** her that the female sexual response is influenced by many factors, not only anatomy/biology (see Table 8.1).

Explain that some of the factors that influence her sexual health can be modified, which can help improve her sexual well-being.
Encourage her to identify and address factors that she can change. For example, she can:

- seek psychological support if she is experiencing mental health problems such as depression or anxiety;
- seek adequate treatment if she is experiencing other health problems; and
- take a proactive approach towards dealing with things that may interfere with moments of intimacy with her husband or partner.

**Encourage** the woman to use the problem-solving approach described in Chapter 7 and in Job aid IV to identify factors that she could change to improve her sexual well-being.

**If relevant, discuss vulvar hygiene** with your patient and remind her that excessive use of intimate hygiene products or practices can interfere with the vagina's natural protection and cause discomfort, irritation and pain in the genital area, especially during sexual intercourse, which can increase the risk of genital infections. 9 If she has severe vaginal dryness, you can suggest the use of a water-based lubricant during sexual intercourse.

#### **REMEMBER:**

Emphasize, whenever possible, that women living with FGM are able to experience sexual pleasure.

#### TALKING ABOUT SEXUALITY AS A COUPLE

When couples learn to talk about their sexuality openly and respectfully, both partners can share their expectations, needs and what they like or dislike. Good communication helps improve the sexual well-being of both members of the couple and also strengthens their relationship.

- Start by acknowledging that talking about sexuality can sometimes be difficult in a couple, but that it is possible to establish good communication if the couple is open to this.
- 2 Ask the woman if she thinks she could talk about sexuality with her husband or partner. If she thinks this is possible, you can **encourage** her to:
  - find a time when her husband or partner is relaxed and then raise the subject of sexuality in the conversation;
  - tell him that having a good sexual relationship can also positively impact his sexual well-being; and
  - identify a private place in the house (or somewhere else) where she and her husband or partner can talk about sexuality, improve their intimacy and perhaps practise things they like to do such as touching, caressing each other and kissing.



## 8.8.3 ENQUIRE ABOUT HER RELATIONSHIP WITH HER HUSBAND OR PARTNER

In some cases, women may be experiencing violence or abuse in their relationship. A fulfilling sexual life and sexual well-being is practically inaccessible for a woman who is suffering domestic violence or sexual abuse, or enduring a difficult marriage. Although this is a sensitive topic, discussing a woman's relationship concerns with her is essential as part of the management of her difficulties with sexual health and well-being.

To open up the discussion, you could ask her:

How is the quality of your relationship with your husband/partner in general?

How are you getting along with your husband/partner?

Be sure to listen attentively, without judgement, and then provide an empathetic response.

**NOTE OF REFERRAL:** *If you suspect or confirm that your patient is experiencing a problem of violence, help to provide her with the necessary information and refer her for further services and social support, as needed.* 

## **IMPORTANT!**

Never raise the issue of partner violence unless the woman is alone.

If you do ask her about violence, use language that is appropriate and relevant to the culture and community you are working in (some women may not like the words "violence" and "abuse"). Use the words that women themselves use.

### ADDITIONAL RESOURCES

Details on providing first-line support for intimate partner violence can be found in the WHO publication, *Health care for women subjected to intimate partner violence or sexual violence: a clinical handbook (30).* 





## 8.8.4 PROMOTE POSITIVE IDEAS ABOUT SEXUALITY

If during the consultation you establish that your patient has certain beliefs about sexuality that may negatively influence her sexual well-being, you can provide the following positive messages that may help clarify these beliefs and frame sexuality in a more positive light (1,31).

- 1 Sexuality is an **important and natural** aspect of being human. It is not something shameful or dirty.
  - All women and men have the **right** to fulfil and express their sexuality and enjoy a healthy sexual life.
- All women, cut and un-cut, can feel curiosity about their bodies, and feel a desire to be caressed and to experience physical intimacy. These feelings are **healthy and natural**. Having undergone FGM does not mean a woman cannot or should not feel them.
- 4 Women living with FGM who experience sexual difficulties can learn, with appropriate **support and care**, to enjoy a fulfilling sexual life.
  - The way a person experiences sexuality evolves and changes with time and experience. Many things can be **learnt and practised** which can lead to an improvement in sexual well-being.

#### **REMEMBER:**

During the consultation, pay attention to the woman's reactions. Some will react with surprise, others will echo the information you have discussed by sharing their own experiences, thoughts, feelings and beliefs. Be respectful of each woman's reactions, but always check that the woman has understood what was discussed. If in doubt, you can ask a few questions regarding a specific subject that was discussed. For example, you can ask her:

Do you think this information can be helpful for you?

What thoughts do you have about what we have discussed?.

Do you want to talk more about this?.

**If the patient does not respond to these invitations, do not insist.** Some women need time before they feel ready to engage with the subject of sexuality. Let your patient know that she can come and see you again by making an appointment when she is ready.



## 8.8.5 OPTIONAL FURTHER EXPLORATION OF FEMALE SEXUAL AWARENESS AND WELL-BEING

Occasionally, a patient may request additional information in the form of concrete suggestions that can help her better understand how to improve her sexual health and well-being. Exploring and practising "sexual awareness" can help the woman better understand her sexual response, which can help her and her husband or partner enjoy their sexual relationship. This involves taking steps to explore and discover her sexual preferences: things she likes and dislikes during sexual intimacy. Here are some suggestions you can offer your patient if requested.

- To become more aware about her sexuality, a woman can start by exploring her thoughts about sexual intimacy ("exploring her head") and her bodily sensations ("exploring her body").
  - "Exploring her head" involves discovering and identifying her thoughts and feelings about sexuality. To practise this, ask her to think about the following statement later at home when she has time alone: "I have a role to play and the ability to enjoy a pleasurable sexual relationship with my husband/partner."
  - "Exploring her body" means becoming familiar with her own bodily sensations. To practise this, ask her to think about the following statement later at home when she has time alone: "I can guide my husband/partner during sexual intimacy towards areas of my body where I like being touched, kissed and caressed."

A woman can practise sexual awareness on her own and with her husband or partner.

 On her own: Encourage her, when she has a few quiet moments to herself, to think about and identify what she enjoys during sexual intimacy. This can help her to be more aware of her sexual response. You can suggest:

Think about things or images you enjoy thinking about before or during sexual intimacy. Keep these in mind during sexual intimacy.

Explore the sensations you feel when gently touching different parts of your body, including your arms, neck or stomach and even the genital area. Try to put words to these feelings.

 With her husband or partner: Suggest that she could find ways of communicating her preferences to her husband or partner during sexual intimacy. You can say:

Use verbal encouragement and reassurance to let your husband or partner know what you enjoy, if you are comfortable doing this.

Whenever you and your husband or partner initiate sexual intimacy, you can start with non-genital touching (such as kissing and caressing) and then slowly, once you are relaxed and at ease, you can move on to having sexual intercourse.



## 8.8.5 CLOSURE AND FOLLOW-UP

Before bringing the consultation session to an end, you should do a brief recap and check if the woman has understood everything and if she has any additional questions or requests. Ask the woman if she would like to return for a follow-up appointment to discuss any of the issues further.

You can also invite her to share what she has learnt with her husband or partner. You can say:

Husbands/partners are also often unsure about female sexual pleasure. They often would like to know more. How would you feel about talking to your husband/partner about this?

Don't insist if she prefers not to talk about this with her husband or partner. It is up to her to decide!



**NOTE OF REFERRAL:** If specialized sexual health services are available, you can refer your patient for further sexual therapy, as needed.

## **REMEMBER:**

## Only offer additional sessions if:

- you feel comfortable and prepared to provide these sessions;
- you have time to do so; and
- the woman is willing to participate in additional sessions.

In case of language barriers, use a certified female interpreter if available (do not ask a friend or a family member of the woman to translate). 8.9 VULVAR SURGERIES AND CLITORAL RECONSTRUCTION Not all women who have undergone FGM require vulvar surgery. This surgery is indicated for women who have severe complications of FGM, such as painful scar tissue and/or symptomatic cysts and keloids that, due to their size, cause persistent discomfort/pain or damage in the genital area or discomfort/pain during sexual intercourse (see further information in Chapter 4).

## **CLITORAL RECONSTRUCTION SURGERY**

Clitoral reconstruction is a surgical procedure that aims to reconstruct the clitoral and/or labial tissues of women who have undergone FGM. Available evidence indicates that reconstructive clitoral surgery can improve chronic clitoral pain as well as dyspareunia symptoms among women who have had clitoral tissue excised or damaged due to FGM (*32*). However, there is little evidence regarding the safety and effectiveness of this surgical procedure in improving women's sexual health, with some women experiencing worsening in sexuality-related outcomes after reconstruction. Women seeking clitoral reconstructive surgery should be informed of this (*33*).

Additional evidence shows that when women with FGM are offered multidisciplinary psychosexual care, including sexual counselling, when they are considering clitoral reconstruction surgery, they often decide not to undergo the procedure and report feeling reassured as a result of the counselling *(18)*. Therefore, it is important to highlight that female sexual well-being does not necessarily involve surgery and that this kind of procedure may not be the right answer for all

women (34). If surgery is considered, it should be contemplated as part of a multidisciplinary approach, which should include medical, psychological and sexological care (18,34,35).

In the case of asymptomatic women living with FGM who request surgery, the management of these cases should preferably start with the least invasive procedure available *(32)*.

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**IMPORTANT!** Deinfibulation improves health and well-being in women who have undergone type III FGM, as well as enabling intercourse (if this is not possible) and facilitating childbirth and urination. Evidence also shows that after deinfibulation women report general improvement in their sexual lives, reduction in pain during intercourse and even increased sexual pleasure (14).

## **REMEMBER:**

Women living with FGM who experience sexual health difficulties can learn the information and skills needed to reach a satisfying and pleasurable sexual life with the help of sexual health education <u>and support</u> services.

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## ADDITIONAL CONSIDERATIONS

# After reading this chapter you should be able to:

- Understand what the ethical standards are for medical professionals in relation to FGM
- Understand why health-care providers should never perform FGM
- Recognize why is it important to have laws that address FGM
- Discuss existing laws with your patients
- Understand what "child protection" means in the context of FGM
- Understand the guiding principles of providing child-friendly care
- Understand what "duty to report FGM" means
- Identify if a girl is at risk of or may have undergone FGM
- Recognize the role of health-care providers in the process of seeking asylum on the grounds of FGM
- Provide care to girls and women who have undergone or are at risk of FGM in conflict, emergency or humanitarian settings

#### In this chapter



# 9.1 PROFESSIONAL ETHICS AND THE MEDICALIZATION OF FGM

#### What are professional ethics?

Professional ethics are moral standards or principles that guide the conduct of individuals working in their respective professions. For those working in the field of medicine or health care, examples include maintaining confidentiality and showing respect for patients as individuals regardless of their cultural background, socioeconomic status or religion *(1)*. Ethics are not based on laws. Most countries have a regulatory or professional body that governs the practice of medicine, midwifery and nursing, to ensure that the ethical standards of each profession are upheld. At an international level, associations such as the International Nursing Council (ICN) and the International Confederation of Midwives (ICM) regulate the practice of nurses and midwives.

[...]

**Medicalization of FGM:** This term refers to situations in which FGM (including re-infibulation) is practised by any category of health-care provider, whether in a public or a private clinic, at home or elsewhere, at any point in time in a woman's life.

# Are health-care providers who perform FGM violating their professional code of ethics?

FGM performed by a health-care provider is contrary to fundamental medical ethical principles. When FGM is conducted by health-care providers this is also known as the "medicalization of FGM"; health-care providers who agree to perform FGM are violating the fundamental medical ethical principle or duty of non-maleficence ("do no harm") and the fundamental principle of providing the highest quality health care possible *(2)*.

**Beneficence:** This word means the act of doing good or the quality of being good, kind or charitable to others. In the medical context, this refers to actions that serve the best interests and promote the well-being of patients.

**Non-maleficence:** This means the avoidance of doing harm or hurting others. In the medical field, this concept is embodied in the phrase "do no harm".

# If performing FGM is a violation of professional medical ethics, why do some health-care providers agree to perform FGM?

In recent years there has been an increase in the proportion of FGM acts carried out by trained health-care providers (medical doctors, nurses, midwives and other trained health workers). Supporters of the medicalization of FGM often claim that by having a trained health worker perform FGM and/or by conducting it in a hygienic environment at a health-care facility, complications can be reduced. Other health-care providers argue that they agree to perform FGM when requested to do so because of a sense of duty to the community and the local culture. However, FGM is not without risk even when performed in sterile conditions, and moreover the removal of or damage to healthy genital tissues brings no health benefit and can instead have negative consequences in the short and long term (*3*).

In some communities, health-care providers may think that FGM is a religious duty. However, FGM is not mentioned in major religious texts. What is more, in communities practising Islam, several eminent scholars have stressed that the few *hadiths* (a saying or action attributed to the Prophet Muhammad) that speak of FGM all lack an authentic *isnad* (chain of narration) and are therefore not reliable as evidence that FGM is a religious duty *(4)*.

#### Is preventing FGM or seeking FGM abandonment a violation of a girl's or a woman's right to practise her culture?

FGM is regarded by the international human rights system as gender discrimination and an act of violence, as well as a violation of the rights of the child when performed on a girl under the age of 18. Performing FGM cannot be justified on the basis of historical, traditional, religious or cultural grounds because it is harmful and violent, and it violates the right of girls and women to bodily integrity.

**REMEMBER:** The right to participate in cultural life does not protect the practice of FGM.

#### **IMPORTANT!**

Health care providers should never perform FGM.

WHO, other United Nations agencies, and international professional bodies such as the ICM, the ICN and the International Federation of Gynecologists and Obstetricians (FIGO), have all declared their opposition to the medicalization of FGM, and have advised that FGM should never, under any circumstances, be performed in health-care facilities or by health-care professionals.

#### **ADDITIONAL RESOURCES**

• Details about Islamic rulings on FGM can be found in the UNICEF publication, *Female circumcision: between the incorrect use of science and the misunderstood doctrine (4).* 

## 9.2 FGM & THE LAW

Recognizing that FGM violates a number of human rights (see Chapter 1 for more information on the human rights violated by the practice), many countries have enacted national laws against FGM which make the act a criminal offence and therefore punishable by law. While some countries have created specific laws against FGM, others use existing laws relating to assault or child abuse as a way to criminalize FGM.

## 9.2.1 THE IMPORTANCE OF LAWS ON FGM AND WHAT HEALTH-CARE PROVIDERS NEED TO KNOW

It is important to have laws that address FGM for the following reasons.

- Laws that address FGM help health-care providers justify their opposition to the practice and give them a good reason why they cannot perform the procedure, even if requested to do so.
- Laws, complemented by culturally sensitive education and public awareness-raising activities, can discourage those who wish to continue the practice and can lead to abandonment (2).
- Legal measures help support those individuals and their families who have abandoned the practice or wish to do so.
- Countries that adopt, implement and enforce legislation addressing FGM affirm their commitment to stopping the practice, and uphold girls' and women's human rights (5).
- At the community level, a law reminds girls, women and their families that girls and women have the right to bodily integrity, and that legal protection from FGM is available and appropriate.

Health-care providers should be aware of the following facts about the legal status of FGM.

- There may be existing applicable laws in the country and healthcare providers should keep themselves informed about these laws and their implications for the provision of health care.
- Health-care providers are required to inform patients and their families that FGM is an unethical practice that cannot be promoted or performed by health-care practitioners.
- While performing FGM is illegal in many countries, providing health care to girls and women who have undergone the procedure is not illegal; in fact, it is required. Refusing care for these girls and women can have a severe negative impact on their health and well-being.
- Deinfibulation is a medically indicated procedure for girls and women with type III FGM. Informed consent must be obtained from the woman or, in the case of a minor, from her parent(s) or guardian(s), prior to carrying out the procedure.
- Re-infibulation is never medically indicated. Regardless of the legal status of FGM or re-infibulation in the country, every effort should be made to discourage the practice of re-infibulation. See Chapter 6 for more information on counselling against re-infibulation. → 6

#### **REMEMBER:**

FGM is a human rights violation from which girls and women need to be protected, regardless of whether or not a country has a specific law against it, including in places where it is considered to be a culturally valued tradition.

## 9.2.2 DISCUSSING THE LAW WITH YOUR PATIENTS

Not all patients will have heard about laws that address FGM. Healthcare providers, as respected members of the community, can take the opportunity during a health-care consultation to raise awareness about FGM and any laws that are in place to protect girls and women from it, and to counsel patients and their families about the implications of violating these laws. This may be especially necessary when you have contact with one or both parents of a girl who you suspect is at risk of FGM, or if you receive a request to perform FGM or re-infibulation. Under such circumstances, health-care providers have the professional obligation to explain the existing laws to the girl or woman and her family members *(6)*.

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**IMPORTANT!** Health-care providers must keep themselves informed about the existence and content of any legislation against FGM in the place where they are working, and they must follow the law and other relevant regulations.

# Following are some suggestions to help you discuss the law with your patients.

When you begin the consultation, which may be for any health concern, **do not start by directly discussing the law on FGM with your patient and her family members;** this could be perceived as intimidating which could interfere with the consultation and undermine your rapport with your patient. First, address any health concerns that your patient has presented with.

When a good moment arises during the consultation for you to raise the issue of the law on FGM, you can open the discussion by asking the woman, or the parents of the girl, if they know that there are laws in place that protect girls and women from FGM. If they do not know, use clear and simple language to explain what these laws say and how they are intended to protect the health and well-being of girls and women.

Explain that those who break the law by taking part in the decision to perform FGM can be punished, even if the community supports the practice.

Emphasize that health-care providers who perform FGM – and in some countries, re-infibulation – risk being suspended from practising medicine and risk facing criminal charges.



**NOTE OF REFERRAL:** Consider referring the family to legal aid services for more detailed information if needed and if possible.

# 9.3 CHILD PROTECTION & FGM

FGM is often performed on young girls and adolescents as well as on infants (7). Despite the fact that members of communities that support FGM do not intend it as an act of abuse, the practice is considered to be a form of violence, and a violation of the rights of a girl child and her bodily integrity. It is also considered to be a violation of a girl's right to protection because it is performed on minors who cannot give consent and may be unable to resist or refuse the practice.



**IMPORTANT:** It is your responsibility to keep yourself informed with up-to-date information about child protection regulations and services in the country where you work, including any existing guidelines about making child protection referrals, if these are available.

#### 9.3.1 CHILD-FRIENDLY CARE

Health-care providers have an important role to play in protecting girls from undergoing FGM and supporting parents who wish to abandon the practice. All health-care providers must consider the needs and well-being of children – this includes providers who care for adult patients.

The following are guiding principles for providing child-friendly care (8).

All children have a right to be protected from abuse and neglect.

Children are individuals with rights – do not unfairly discriminate against a child for any reason.

Always approach children with great sensitivity, recognizing their vulnerability.

Never blame the child.

Children have a right to be involved in their own care – this includes the right to receive information that is appropriate to their level of maturity and understanding, the right to be heard and the right to be involved in major decisions about them, in line with their developing capacity.

#### 9.3.2 DUTY TO REPORT FGM

A duty to report FGM means health-care providers should report to an appropriate agency – such as the local authority children's services, social services or the police – if during their professional work they suspect or confirm that a girl under 18 years of age:

is at risk of FGM, or

has undergone FGM.

**Child protection:** Includes measures to prevent and respond to violence, exploitation or abuse against children, including harmful traditional practices, such as FGM and child marriage. Child protection calls for children to live free of violence and discrimination (7).

**Mandatory duty to report:** In some countries, there is a mandatory duty to report FGM, which means that health-care providers are legally required to report if a girl under 18 years of age is at risk of FGM or has undergone FGM.

#### **REMEMBER:**

By reporting, you are not making the final decision about how best to protect a girl; that is the role of the local authority children's services and, ultimately, the courts.

Even if it turns out that the girl is not at risk of FGM, reporting will be justified as long as your concerns are honestly held and reasonable (8).



**IMPORTANT:** You do not need to be certain that a girl is at risk of FGM to report. If you suspect a girl is at risk of, or is suffering due to FGM, the potential negative consequences of not reporting this information will, in the vast majority of cases, be far greater than any harm caused by sharing your concerns (8).

#### 9.3.3 IDENTIFYING GIRLS AT RISK OF FGM

## How do I know if a girl is at risk of or has recently undergone FGM?

Health-care providers must be aware of the possible physical, psychological and behavioural signs that may be present in a girl who has undergone FGM or a girl who might be at risk of the practice. You should also know where to refer the girl if an examination is needed to assess her health and other needs.

#### SIGNS THAT A GIRL COULD BE AT RISK OF FGM

She or a sibling asks you for help; a parent or other family member tells you that FGM may be carried out on the girl; or the girl informs you that she is to have a "special procedure" or is to be "recognized as a woman" or is to "become like my sister or mother".

A forced marriage is suspected or known. In addition to addressing this, the risk of FGM should also be addressed if the girl comes from a community that traditionally practises FGM.

There has been repeated failure to get the girl to attend or engage with health and welfare services (e.g. to attend health-care appointments), or the girl's mother is very reluctant for her to undergo a genital examination.

She is withdrawn from school to allow for an extended holiday, or she talks about a planned trip either to go abroad or to her family's community where FGM is widely practised. Her father or mother or both are from a community or ethnic group known to practise FGM.

You hear FGM referred to in conversation by the girl, her family members or close friends.

Her sister, mother or cousin of a similar age have been cut.

Her parents express views that are supportive of the practice.

If a woman who has recently given birth (and/or her husband or other family member) requests that she be re-infibulated following childbirth, then her baby may also be at risk of FGM, if the baby is a girl.

## SIGNS THAT A GIRL MAY HAVE RECENTLY UNDERGONE FGM (9)

- She has difficulty walking, sitting or standing.
- She spends longer than normal in the toilet and has difficulty urinating.
- She has frequent and/or unusual bladder or menstrual problems.
- She returns after a long absence from school with mood or behaviour changes (e.g. she is withdrawn or depressed).
- She is particularly reluctant to undergo normal medical examinations.
- She has asked for help or advice but has not been explicit about FGM due to embarrassment or fear.

### BOX 9.1 Safety plan for girls at risk of FGM: creating a local directory of child protection services

As a health-care provider, in order to adequately protect girls at risk of FGM, it is your duty to find out about any existing FGM reporting regulations (and the related professional protocols and guidelines), as well as any existing children's support services. Even in settings where official regulations, protocols and services are not available, you can create a local directory of any known child protection and support services. This directory should include:

- type of service offered
- name and address of the institution providing the service
- name(s) and contact details for the person(s) responsible
- hours and days of service.

## 9.3.4 MEDICAL EXAMINATION OF A GIRL WHO IS AT RISK OF OR HAS UNDERGONE FGM

A medical examination of a girl (i.e. a minor, under the age of 18) who is at risk of or has undergone FGM should be conducted according to national child protection procedures and as indicated by national regulations or medical standards. Normally, this will be conducted by a specialized medical or forensic professional, such as a health-care provider with forensic training or a medico-legal examiner, who has experience dealing with cases of FGM. Before performing the examination, informed consent from the girl and her parents/legal guardians or from the necessary authorities must always be obtained (10).



**IMPORTANT!** Please refer to your professional regulatory body and the national ministry or department of health to find out what the rules and regulations are regarding reporting and recording known or suspected cases of FGM in the country where you are working.

## 9.4 FGM & ASYLUM

This section aims to provide information for health-care providers working in countries that receive people who make asylum claims based on FGM. Claims can be made by parents on behalf of their daughters, and by girls and adult women on their own behalf.

FGM is recognized as a human rights violation by international and regional human rights laws, and constitutes a form of genderbased violence that inflicts severe harm, both mental and physical, on girls and women. It is also considered a form of persecution under the 1951 Geneva Refugee Convention (11). In addition, FGM violates the right of the child to be protected against harmful practices. Thus, a person can seek asylum and qualify for refugee status if she is likely to be subjected to FGM or she has been forced to undergo the procedure. A parent can also seek asylum for a girl at risk of FGM (12).

## 9.4.1 ASYLUM SEEKING ON GROUNDS OF FGM

Claiming asylum on grounds of FGM is possible in different situations. Those who may be able to claim asylum on these grounds include (*11,12*):

girls (unaccompanied or separated from their families) and women who seek protection from being subjected to FGM;

girls and women who have already undergone FGM and who seek deinfibulation or protection from re-excision or re-infibulation upon marriage or at childbirth;

women living with FGM who have had genital reconstructive surgery or deinfibulation (often abroad) and who fear being cut again or re-infibulated if they return to their country of origin;

parents who seek international protection to protect their daughters from FGM;

women who are under pressure from their families and/or communities in their countries of origin to cut their daughters, but who refuse to do so; and

activists (both women and men) who are persecuted for their opinions and commitment to end FGM in their countries of origin.

#### 9.4.2 THE ROLE OF HEALTH-CARE PROVIDERS IN ASYLUM REQUESTS

In today's globalized world, health-care providers in various settings may encounter female patients who have undergone or are at risk of FGM, and who are seeking asylum on the grounds of the practice. It is the health-care provider's role to provide support and care to these asylum seekers and, very importantly, to identify vulnerable girls and women at an early stage. Yet, there are a number of obstacles to meeting the specific protection needs and vulnerabilities of these women and girls. In particular, communication and disclosure of information can be very difficult, hindered by the barriers listed in Box 9.2.

#### BOX 9.2 Barriers to communication in the context of asylum requests

New asylum seekers often do not speak the language of the country they are in.

X

FGM is usually a taboo subject about which many girls and women do not want to speak, or about which they feel extremely uncomfortable speaking, since it can involve disclosing a traumatic experience, or an experience they consider shameful and which they want to hide.

Girls and women may have difficulty discussing FGM due to mistrust of authority figures and/or lack of education.

X

They may also be experiencing post-traumatic stress disorder (PTSD) or other mental health problems or disorders.

Some girls and women who are asylum seekers do not see FGM as a violation of their rights nor realize the impact of FGM on their health.



Health-care providers in recipient countries are often not familiar with FGM nor the asylum-seeking process. This can lead to misconceptions on their part, such as a belief that FGM is not a problem for these girls and women (or families) because it is part of their culture, or that educated parents should be able to protect their daughters from it *(12)*. A critical step in overcoming these barriers is to ensure that healthcare providers are well informed about FGM and the asylum-seeking process in the country where they are working. When providing health care to asylum seekers, as a health-care provider you must make sure you do the following (12,13).

- 1 Keep yourself well informed about the consequences of FGM on health and the legal status of the procedure in the receiving country, and discuss this with your female patient. This will help girls and women understand that they have been (or are at risk of becoming) victims of violence, which may give them grounds for asylum. It can also help prevent FGM for other family members.
  - Inform the asylum seeker about her rights the right to seek appropriate medical and mental health care and the right to seek asylum as a victim or potential victim of gender-based violence.
  - Provide the asylum seeker with information about the asylum process in a language that she can understand, as the process is new to most of them and highly complex. Understanding the asylum procedure will prepare them for having to give their testimony to the asylum authorities – an important step in the asylum process.

**Use trained interpreters, if needed – preferably female –** who can provide an accurate translation during the consultation. See Chapter 2.

5

When prescribing treatment, be aware of the list of drugs or surgical acts effectively covered by asylum authorities in the country where you work. Treatment that is not considered to be essential and urgent is usually not reimbursed.

When providing care for an unaccompanied child who is applying for asylum, ensure than both the interviewing techniques and the credibility assessment are appropriate for a minor. If necessary, refer the child to specialized professionals.

**NOTE OF REFERRAL:** *If you cannot provide care, refer the girl or woman to a health-care provider who can provide appropriate medical or psychological care and treatment, as needed.* 

7

Keep yourself informed about – and refer girls and women to – existing services that offer legal advice for immigrants. Immigration specialists will be able to explain in greater detail how the case for asylum on grounds of FGM needs to be put forward.

This will depend on the rules and regulations supporting each country's immigration laws.

#### 9.4.3 MEDICAL EXAMINATIONS AND MEDICAL CERTIFICATES RELATING TO FGM

#### MEDICAL EXAMINATION

In some cases, it may be necessary to conduct a medical examination, including a genital examination, with the patient's consent to assess the physical health problems related to FGM as a basis for providing adequate treatment and care. Health-care providers should be aware that the information collected may be required as medical evidence for the asylum process.



#### IN CASES OF CHILDREN

Special attention should be given to children (girls) who may be seeking asylum on grounds of FGM. As stated in section 9.3.2, health-care providers must report to an appropriate child protection authority if they suspect or confirm that a girl is at risk of or has undergone FGM. It is important to note that the appearance of a normal vulva in pre-pubertal girls may lead to false diagnosis of FGM if the health-care provider is not used to examining children. In some countries, only doctors or paediatricians with forensic training or medico-legal examiners can issue medical certificates relating to FGM for girls under 18 years of age (see section 9.3.4 for more information on the examination of girls). → 9.3 The following information should be recorded during the examination:

description of the external genitalia and the type of FGM identified, using the WHO classification;

any other scars on the perineum or inner thighs (e.g. cigarettes burns);

any health complications related to FGM;

any additional medical conditions identified during the genital examination.

This information will need to be included in a medical certificate if one is required (see next page).



**NOTE OF REFERRAL:** If the girl or woman has been a victim of torture and has several scars on her body, refer her to a doctor or other health-care provider (e.g. a nurse) with forensic training, or a medico-legal examiner, for further examination (14).

#### PREPARING A MEDICAL CERTIFICATE RELATING TO FGM

Some authorities handling asylum seekers' applications will provide health-care providers with medical forms that should be filled out according to their specific instructions and returned to them for processing. However, sometimes there are no such medical forms and instead the health-care provider will need to prepare a medical certificate (i.e. a signed and stamped official letter containing the information listed on the previous page) and send this to the authorities. In this case, it is important to include the details listed on the previous page, which should have been noted during the medical examination; this helps in characterizing FGM as a continuous form of persecution (15).



In the case of girls and young women asking to be protected from FGM, asylum authorities may ask for a medical certificate proving the integrity of their external genitalia. A medical examination of a girl for such purposes should always be conducted according to national child protection procedures and as indicated by national regulations or medical standards (see section 9.3.4 for more information on the examination of girls). A psychological report describing the psychological consequences of FGM (which is often coupled with other forms of violence) can support the medical certificate. These documents should be prepared by a professional trained in providing psychological care.

## 9.5 FGM IN CONFLICT, EMERGENCY OR HUMANITARIAN SETTINGS

Health-care providers working in conflict, emergency or humanitarian settings may come into contact with displaced communities or populations that practise FGM. In these settings, you may also come across displaced people or groups from communities that do not normally practise FGM but who have started the practice after migrating to areas where it is practised.
#### PROVIDING HEALTH CARE IN CONFLICT, EMERGENCY OR HUMANITARIAN SETTINGS

In these settings, make sure that health services:

are ideally within walking distance to where communities live, and in a safe location;

are open and available at times of the day when girls and women can attend;

include a private space for consultation and examination; and

have interpreters available or other arrangements to address language and communication barriers (for more information on working with interpreters, see Chapter 2). → 2

#### cultural note $\mathcal{Q}$

Be aware of potential cultural constraints, such as the fact that girls who are unmarried or below a certain age may not be allowed to access reproductive health services, or their attendance (if observed by others) may be noted or questioned and have negative consequences for them. Providing reproductive health information sessions at schools can help overcome these barriers for adolescent girls.

#### HOW HEALTH-CARE PROVIDERS IN CONFLICT, EMERGENCY AND HUMANITARIAN SETTINGS CAN BETTER CARE FOR GIRLS AND WOMEN WHO HAVE UNDERGONE FGM (16)

- 1 Inform yourself and other members of the health-care staff about whether or not FGM is practised by the local and displaced communities. Details such as what is the most common type of FGM, the typical age of cutting, and the estimated prevalence of the practice are important for you to know.
  - Inform yourself of the local laws on FGM and your obligations as health-care providers, under those laws, with regard to reporting. See section 9.3.2 for more information on the duty to report FGM.
    - If available, familiarize yourself with local FGM management protocols, and make sure they are available for all health staff.
    - If FGM-related protocols and guidelines are not available, identify fellow health-care providers who have experience caring for girls and women living with FGM and consider organizing a workshop or information session for health-care staff using the information in this handbook to teach them about the basic health needs of this population and how to provide better care.
      - Make sure FGM status and type is routinely recorded in girls' and women's medical records.

#### **REMEMBER:**

All the recommendations on treatment, care and protection from FGM provided in this handbook apply in conflict, emergency and humanitarian settings, just as in other settings. 9.5

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Care of girls & woman living with female genital mutilation: a clinical handbook

# CLASSIFICATION OF FGM

WHO classifies FGM into four types, as described in the following diagrams.



#### ΤΥΡΕ Ι

Partial or total removal of the clitoral glans (clitoridectomy) and/or the prepuce



Type la: removal of the prepuce/clitoral hood (circumcision)

**Type lb:** removal of the clitoral glans with the prepuce (clitoridectomy)

#### TYPE II

Partial or total removal of the clitoral glans and the labia minora, with or without excision of the labia majora (excision)



Type IIa: removal of the labia minora only

**Type IIb:** partial or total removal of the clitoral glans and the labia minora (*prepuce may be affected*)



**Type llc:** partial or total removal of the clitoral glans, the labia minora and the labia majora *(prepuce may be affected)* 

#### TYPE III

Narrowing of the vaginal opening with the creation of a covering seal by cutting and appositioning the labia minora or labia majora with or without excision of the clitoral prepuce and glans (infibulation)



**Type Illa:** + + + appositioning of the labia minora



Type IIIb: + + + + + appositioning of the labia majora

#### TYPE IV

All other harmful procedures to the female genitalia for non-medical purposes, for example pricking, piercing, incising, scraping and cauterization



# VISUAL RECORDING OF FGM

The identification and recording of FGM can sometimes be challenging, especially when a girl's or woman's genital cutting does not look exactly the same as that described in the WHO typology.

If after performing a genital examination you cannot determine exactly the type of FGM your patient has undergone, you should at least record that she has undergone FGM (i.e. her genitalia are not unaltered as shown in Figure 1) and describe which anatomical structures have been removed or damaged.

Figures 1–6 are examples of hand-made drawings that depict some types of FGM. Keep in mind that some girls or women may have different forms of FGM and therefore you should always develop your own drawings to put in the patient's medical record based on the findings of the genital examination. All structures affected should be noted.





Figure 1 Diagram of unaltered genitalia



*Figure 3* Type I: prepuce and clitoral glans removed



Figure 5 Type IIIa: labia minora closed



Figure 2 Drawing of unaltered genitalia



*Figure 4* Type II: prepuce, clitoral glans and labia majora removed



Figure 6 Type IIIb: labia majora closed

## III

# THE DEINFIBULATION PROCEDURE

#### IN PREPARATION FOR THE PROCEDURE

#### Explain...

In order to prepare the woman (and her husband/partner if appropriate), give clear and full information about the procedure and make sure she has understood. Ask the woman if she has any questions (see Chapter 6).  $\bigcirc$  6

#### Preparation of equipment and materials

Prepare a tray with:

- a pair of sterile gloves
- antiseptic swabs and dressings
- a pair of straight Metzenbaum scissors of curved Mayo scissors (depending on the thickness of the tissue)
- a pair of suture scissors
- a pair of surgical tweezers
- a dilator (if available)
- two artery forceps
- a needle holder
- sterile swabs



Vorld Health Organization

- 10-ml syringe and needles for injection
- local anaesthetic (such as Lidocaine)
- 3-0 absorbable suturing material
- sterile towel/surgical cloth
- antiseptic solution
- a receptacle for used instruments.

#### THE DEINFIBULATION PROCEDURE

- Ask the woman to lie on her back on the examining table.
- Wash your hands and put on gloves.

Use medicated soap and water or alcohol-based hand-rub for hand hygiene.

- Expose the genitalia and clean the perineal area with antiseptic swabs.
- Start by palpating the scar tissue in order to identify underlying structures (urethral meatus). This will help guide the procedure.
- Gently introduce your index finger or both your index and middle fingers – or a dilator – under the hood of skin anteriorly and slightly lift the scar tissue (see Figure 1).
- Infiltrate local anaesthetic into the area where the cut will be made, along and on both sides of the scar (if the woman has received epidural anaesthesia there is no need to administer local anaesthetic) (see Figure 2).



Figure 1





With your finger or dilator under the scar, carefully introduce the scissors in front of your finger and cut the scar alongside your finger to avoid injury to the adjacent tissues (or to the baby, if the procedure is done during childbirth) (see Figures 3 and 4).

The cut should be made along the mid-line of the scar towards the pubis to expose the urethral opening.

Do not incise beyond the urethra. Extending the incision forward may cause haemorrhage.

Take care not to cause injury to the structures underneath the scar (urethra, labia minora and clitoris). It is possible with type III FGM to find these structures below the scar intact.

Inspect the cut edges for bleeding points and perform haemostasis if needed. Generally speaking, there is little bleeding for the relatively avascular scar tissue.

Suture the raw edges separately with individual stitches. Use fine 3-0 plain, absorbable suturing material to secure haemostasis and prevent adhesion formation (see Figures 5 and 6).

Prescribe oral analgesia following the deinfibulation.

#### IMPORTANT!

Opening up an infibulation should only be done after the woman has been thoroughly counselled and has given consent (unless it is an emergency situation when the woman is already in advanced labour). See Chapter 6.



Figure 3



Figure 4



Figure 5





## PROBLEM MANAGEMENT IN FIVE STEPS

You can help your patient manage problems by walking her through these five steps.

#### IDENTIFY THE KEY PROBLEM

- Make two lists:
  - problems that are solvable, and
  - problems that cannot be solved.
- Choose the most important problem from the "solvable" list.
- Clarify what the problem is and break it down into manageable parts.

#### BRAINSTORM

Assist the patient to generate possible strategies to address the problem

- Are there resources she can use?
- Are there people or agencies who can help?
- Are there other sources of support?
- What skills and strengths does she have that she can use to deal with the problem?
- Encourage her to come up with ideas; avoid giving her advice. You can ask her, for example: "If a friend had this problem, what would you advise her to do?"







#### 3 CHOOSE WHICH STRATEGY OR • STRATEGIES TO TRY

- Which would be the most effective?
- Which is easiest?
- Which one can she carry out (e.g. based on her financial means)?

### **4** TAKE ACTION AND USE THE STRATEGIES

- Make a detailed plan with your patient.
- Help her decide which strategy she will try first (if she has chosen more than one).
- Help her choose the best times and places to carry out the strategy (e.g. it may help if the planned actions coincide with routine activities).
- Discuss what she will need to take action (e.g. money, transportation, etc.).
- Discuss any possible obstacles.
- Create reminders (e.g. use a calendar/diary or other notes).

#### **REVIEW WHAT HAPPENED**

(This step should be done in a follow-up session.)

- What strategy worked well?
- What goals were achieved?
- What could be done better?
- What are the next steps?



*Source:* Adapted from Problem Management Plus (PM+): individual psychological help for adults impaired by distress in communities exposed to adversity. (Generic field-trial version 1.0). Geneva: World Health Organization; 2016.

## DIAGRAMS OF THE FEMALE GENITALIA



Figure 1: Anatomical structures of the female vulva

The female vulva comprises several anatomical structures that are involved in the female sexual response. One or several of these structures may be harmed by FGM.



Job aid

The clitoris is a boomerang-shaped organ located below the pubic symphysis. Its function is to provide sexual pleasure to the woman. Anatomically, the clitoris has both external (the clitoral glans) and internal structures (the clitoral body and the crura); the latter are located inside the woman's body.



Figure 2: Anatomical structure of the clitoris

Figure 3: Anatomical structure of the clitoris in profile view

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