Chapter 1 Assessing the Infant/Child/Young Person with Suspected FGM/C



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1.1 How Does the Child First Present?

The majority of HCPs in high-income countries are unlikely to see children with FGM/C who may be acutely unwell on account of cutting (that is, due directly to the procedure itself). Hemorrhage, infection, and sepsis are among the potential acute complications of FGM/C, especially with more severe types and if carried out with non-sterile equipment by a medically unqualified practitioner [12]. Although the absolute likelihood of these complications is not known and depends on the type of cutting, the instruments used, the skill of the person doing the cutting, and the (lack of) clinical adequacy of setting, when complications do occur, they may be life-threatening [13]. If called to see a child immediately after FGM/C, management should include assessment for signs of acute blood loss, infection, or urinary retention and treatment with antibiotics, analgesia, tetanus toxoid, and urinary catheterization, should be administered as clinically indicated. Attention should also be made to local laws regarding the performance of FGM/C in children. The clinician should follow local requirements for reporting the suspected case to the appropriate child protective and child abuse services [14, 15].

An I/C/YP may be referred to an HCP for assessment for FGM/C in various scenarios, depending on the country where the I/C/YP currently resides and local

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laws that may dictate the approach. These scenarios may include evaluations simply because the I/C/YP comes from a country where FGM/C is practiced or because FGM/C has been alleged by the child herself or by a family member; or following concerns raised by a teacher, a medical or mental health provider, social service provider or the police. In some high-income countries, a referral might also be a result of an immigration process for individuals seeking asylum, with the request to confirm or exclude the presence of FGM/C. In health care settings, FGM/C may be encountered during evaluation of relevant history and symptoms, including recurrent urinary tract infections; vulvitis or other genitourinary complaints; when a child is referred for a medical assessment of maltreatment or during physical examinations carried out on unaccompanied child migrant or adopted I/C/YP. FGM/C may also be discovered during standard annual physical examinations. When a pregnant female with FGM/C presents for the birth of a child, antenatal, and/or postnatal appointments, she should routinely be asked if any of her children have had FGM/C, whereupon the HCP should assess the immediate and future risk to her children and discuss medical and legal ramifications of having FGM/C performed on any children. If her children have had a history of FGM/C, arrangements should be proposed to have her children evaluated and treated as needed [16].

The primary aim of the clinical assessment is to confirm, if possible, whether FGM/C has been performed. If FGM/C is confirmed then subsequent management includes:

- 1. Identifying and managing immediate and long-term health consequences for the I/C/YP.
- 2. Providing culturally sensitive, age-appropriate, and non-stigmatizing information to her and her family.
- 3. Evaluating the risk to other children in the immediate and extended family and if needed, carrying out an appropriate assessment. This may include linking other children and adults with FGM/C, or at risk for the practice, to appropriate ongoing medical and mental health care, as needed. In some countries, medical corroboration might instigate a police investigation and criminal prosecution.
- 4. Providing counselling to expectant parents about FGM/C medical complications and illegality.

1.2 Clinical Setting

Examining children with suspected FGM/C is a relatively new requirement in several high-income countries and is performed by different specialists [9, 10, 17]. It is considered best practice to assess I/C/YP with suspected FGM/C in a child-centered setting and according to local clinical practices and resources. The setting, professionals involved, and nature of case identification vary between countries. In the UK the I/C/YP is seen by a multidisciplinary team [10, 17, 18]; in Belgium and Switzerland, the I/C/YP is examined by a gynecologist trained in FGM/C and/or a pediatrician or a child-and-adolescent gynecologist; in France, children are seen by a forensic examiner; in the US, girls with or at risk of FGM/C who are seeking asylum may be examined by a medical forensic examiner, may be identified as part of standard refugee domestic medical screening, or may be diagnosed at standard annual physical examinations, or because of symptoms related to FGM/C. The examining clinician must have experience in the genital examination of children and should be trained in identifying the different types of FGM/C [19]. However, many countries may not have this degree of training available. In such cases, if resources are available, it is recommended to develop specific regional centers with HCPs who can serve as consultants. FGM/C examinations may also be provided by existing clinics such as those that see and perform evaluations on I/C/YP who are alleged victims of acute sexual assault or suspected sexual abuse, or by medical forensic examiners/specialists. Clinicians working in these service areas are highly skilled at genital examination of girls but often have less experience in detecting the physical signs of FGM/C [20]. Close examination of the clitoris and peri-clitoral area is not common when examining for child sexual abuse (CSA) but is essential when performing an evaluation for FGM/C. HCPs should not miss the opportunity during CSA assessments to gain experience in recognizing normal variants of clitoral anatomy [21, 22], which will help in distinguishing such variants from FGM/C.

The lead clinician in the evaluation of a child for FGM/C may be a pediatrician, gynecologist, pediatric gynecologist, general practitioner, urogynecologist, child abuse pediatrician, specialized nurse, sexual health clinician, or forensic examiner. Where resources and services are available, they should work within a multidisciplinary team with access to psychological support for the child and the family, whether or not FGM/C is confirmed. A play therapist can help prepare younger children for the examination using dolls. It is recommended that the service will also offer referrals to local community-based support, if available. In order to prevent repeated, and possibly traumatic examinations, access to a central service which offers an expert review of images and DVDs is recommended after informed consent. If no video recordings or images are available in the country where the evaluation takes place, precise documentation and drawings should be used to detail physical findings.

1.3 Taking the History

If the girl is old enough with the developmental capability needed, it is important to first take the history directly from her so that she can understand that the consultation is about her health and well-being. More details of the history can be obtained from the social worker and parents/legal guardians/caregivers, recognizing that the parents/ legal guardians/caregivers may have been perpetrators of the FGM/C. At the beginning of the visit, the clinician should explain why the examination has been suggested. The clinician should also obtain information from family members, such as the mother or father, about any family history of FGM/C. A medical history should be taken with the aid of the parents/guardians/caregivers and should include questions about developmental milestones and general health. Place of birth, ethnic group, date of entry to the country, and travel details abroad are relevant. Questions specifically addressing physical or psychological symptoms that may be associated with FGM/C are important (Table 1.1) [16]. A standardized form will ensure that all important questions are being asked (Appendix of chapter "Consent and Photography") [18,

Possible short-term health complications of FGM/C	Severe local pain
	Injury to tissues
	Hemorrhage
	Hemorrhagic shock
	Infection and septicemia
	Genital tissue swelling
	Acute urine retention
	Death
Possible long-term health complications of FGM/C	Chronic vulvar pain
	Dyspareunia
	Clitoral neuroma
	Menstrual difficulties
	Painful or difficult urination
	Keloids in the genital area
	Reproductive tract infections
	Urinary tract infections
	Epidermal inclusion cysts in the genital area
	Post traumatic stress disorder (PTSD)
	Depression and anxiety
	Psychosexual dysfunction

Table 1.1 Physical and psychological consequences of FGM/C

23]. It is important to bear in mind that although many medical complaints may be attributed to FGM/C, some symptoms such as dysmenorrhea, obstructed menstrual or urinary flow, genitourinary infections, or dyspareunia may be unrelated and could be due to another medical condition, while psychological symptoms could be related to a wide range of factors unrelated to FGM/C. Many I/C/YP who have experienced FGM/C might be more occupied with their daily life and challenges than they are by their FGM/C, which they may not even remember having gone through. It is important not to cause iatrogenic harm by using terms or questions which might lead children to become ashamed of their bodies, to feel "not normal," inadequate or subject them to other stigmatization [24, 25]. Medical providers may identify FGM/C in infants, children, and adolescent girls outside of a formal evaluation. In such cases, it is important to discuss the findings with the child (if age-appropriate) and parents/ legal guardians. If the patient is an adolescent girl and does not want such findings disclosed or discussed with the legal guardians and there are no urgent medical issues related to the FGM/C, medical providers, should follow local laws regarding protected health information and approach the discussions per those country guidelines.

Age-appropriate language is important and accredited, independent interpreters should take part in the consultation using the language understood by the I/C/ YP. Family members and/or friends should never act as interpreters.

1.4 The Examination

If a medical provider is examining an infant or a child during the standard physical examination for annual well child care or for medical complaints necessitating an external genital examination, assent of the child should be obtained and documented together with the consent from the parent or legal guardian, who may remain in the room throughout the examination. If the evaluation is for an adolescent female

presenting for a confidential visit, she may provide consent for an external genital examination without parental involvement. Whenever feasible, gender concordance should be optimized between the patient and health provider and all genital examinations should be chaperoned by a medical staff (regardless of gender).

If the evaluation is part of formal investigation, assent should be obtained from the girl (if age-appropriate) and consent from the legal guardian/parent before the examination (see chapter "Consent and Photography"). Written consent should be obtained for any photographic or video images or recordings taken during the examination (DVD, for example). Assent should be obtained in an ongoing fashion throughout the examination, especially before conducting the genital examination. The extent of the physical examination will depend on the age of the girl and her understanding of the examination. Young girls may be told that they are about to have a general "check-up." After height, weight, an examination of ears, heart, or lungs may precede the genital inspection to help lessen anxiety and normalize the process. Older girls usually have a better understanding of why an examination is needed/being carried out. Genital examination of children for FGM/C should be performed as gently and as speedily as possible in a sensitive age-appropriate manner. A critical part of a trauma-informed and survivor-centered approach is to create a safe environment for the child, clearly describe the purpose of the evaluation, and provide a description of every step of the physical examination. The patient must be reassured that she may pause or even stop the evaluation at any time. In situations where the patient may decline an examination despite counseling, it is advised to create safe spaces; use open bidirectional dialog; reduce stigma; further delineate critical steps that can be taken to facilitate trust-building; guarantee continuity of follow-up care and referral for psychological counseling if appropriate [14, 18].

An internal vaginal examination is almost never required for the assessment of FGM/C, and this should be made clear to the girl and her family from the outset. Full disrobing and undressing is not required and could be traumatizing. In many circumstances pulling one leg out of the knickers [underpants] will permit sufficient exposure and may be more acceptable to some girls and families.

The child may be examined in the frog-legged or in the knee-chest position (Fig. 3.1 of chapter "Pictures Without FGM/C and Without Lesions"). A younger girl can have the nappy [diaper] changed or sit on her parent/guardian/caregiver's lap.

The genitalia are inspected with gentle labial traction in order to expose the skin folds (Fig. 3.2 of chapter "Pictures Without FGM/C and Without Lesions"). If the girl is able to cooperate, the examiner's gloved thumbs may be placed on the inner face of the outer labia and gentle traction applied laterally and downwards to reveal the inter labial sulcus and the clitoral eminence [26].

Where available, a colposcope is recommended for adequate lighting and magnification. With specific consent, colposcopic images may be recorded which can be later peer-reviewed when seeking an expert opinion. In addition, in the case of legal proceedings photo documentation of FGM/C is highly recommended but should be obtained without coercion and only with full informed consent of the legal guardian and the child, when appropriate. Images must be labeled and stored, as part of the medical file in a secure platform, as for all storage of intimate images and personal health information as is required for all. Adolescent girls with FGM/C may choose to watch the colposcopic video screen during the examination, which can be educational and informative and allow for a neutral and open exchange about the genitalia and findings. If video visualization is not available, the adolescent may also be offered a hand mirror in order to demonstrate and explain the findings.

A diagram or photograph with labels should be used to indicate any identified anatomical changes (Fig. 3.5 of chapter "Pictures Without FGM/C and Without Lesions"). The WHO classification may be used to describe the type of FGM/C [4].

HCPs and patients must be aware that FGM/C does not always leave physical traces and that the crura, part of the body of clitoris, and the vestibular bulbs are never removed during FGM/C.

It is assumed by some that FGM/C is easily detected on genital inspection but often this is not true. While Type III FGM/C is easily noted, other types of FGM/C are more difficult to diagnose with confidence. This is particularly true for Type IV FGM/C which may comprise only a prick or a small scratch on (or adjacent to) the clitoral glans or hood. This may heal completely leaving either no scar or a small scar, either of which is difficult to detect upon visual inspection, especially if the examination takes place months to years after the procedure has happened. Thus, a normal genital examination cannot exclude Type IV FGM/C. In this situation, the diagnosis will be based on the girl's or parents' history. Examiners must also be familiar with the differences between a pre and postpubertal vulva. The inner labia are underdeveloped prior to pubertal hormonal changes and this must not be mistaken for removed labia. Labial adhesions following inflammatory processes, hypoestrogenic state, lichen sclerosus, or other vulvar dermatoses can be confused with infibulation. Small irregularities in the skin of the vulva or clitoris can simply be a result of anatomical variation. In addition, examiners must realize that it is impossible to deduce a timeline for an FGM/C procedure based on physical evidence (unless acute) and criminal investigators' requests for such a timeline should be rejected.

Once the examination is completed, the findings should be discussed with the family and the girl, taking into account the context, confidentiality rules, local laws, and resources. Depending on the situation and the country, some findings might also be discussed with social service providers (i.e., child protective services), forensic examiners, and lawyers with consent/assent by the patient and parent/guardian (i.e., during asylum-seeking procedures or crime investigations). It is best to provide expert assessments and conclusions only in the specific field in which you are trained, experienced, and have expertise for which, regular updates of the sociocultural context and processes of cultural change take place. The process of clinical judgment should be aided by obtaining or by asking for a second opinion in when there are doubtful or equivocal findings; and, when possible, working within a multispecialty/cross-sectoral team is recommended.

It is also necessary to use data, clinical history, and examination findings when evaluating possible future long-term health consequences related to FGM/C to assure that the findings are based on evidence [27].

When age, developmental stage, and level of understanding are appropriate, it is recommended that FGM/C is explained to the girl, including possible consequences to her future health. These explanations should be conveyed in a clear, sensitive and honest manner depending on her age, developmental stage, and her level of

understanding. Diagrams of both FGM/C affected and uncut female genitalia are useful tools when explaining the clinical findings in detail. Audiovisual and/or verbal information, in a language the family is familiar with and providing information about community support organizations are helpful if the family and the girl are literate in a given language. For preliterate families, it is recommended to provide detailed explanations, the provision of information, diagrams, and to also link girls and families to community support organizations, as desired.

A community approach to prevention is key, as some families may not know that FGM/C is illegal in their country of residence [28].

1.5 When FGM/C Is Confirmed

1.5.1 Clinical Management

If FGM/C is confirmed, testing for blood-borne viruses (BBV) including Hepatitis B and C and HIV should be considered, though data is limited on actual transmission rates. Other tests will depend on clinical findings and history. If the child has urinary symptoms, a midstream specimen of urine for urinalysis, culture, and sensitivity may be indicated. The most common symptoms in children attributed to Type III FGM/C are urinary and some symptomatic I/C/YP may require deinfibulation [23, 29]. However, only 10–15% of FGM/C cases are classified as Type III, therefore most girls with FGM/C will not need de-infibulation [2, 30].

De-infibulation is generally a same-day procedure, often in a pediatric surgical unit and using brief general anesthetic or intravenous sedation. For those who have experienced Type III FGM/C and are asymptomatic, the timing of de-infibulation must be discussed with the girl and her guardian(s). Girls aged 16 years or older may be suitable for an outpatient/day surgery procedure and can be offered this option [6]. Older girls with Type III FGM/C who are asymptomatic often choose to defer de-infibulation until they are ready to consider sexual intercourse. In this case, contact details of the available adult services should be made available to them. Not all adolescent females want their families to know when or if they choose to undergo de-infibulation. Because de-infibulation is an outpatient procedure for older adolescents and adults, in some countries, it can be done without informing the family, though familiarity with local legal codes is recommended. In other countries, child protective services may need to be involved in order to obtain legal consent to proceed [11]. A common fear related to de-infibulation is the loss of premarital virginity [6], often based on a husband's expectation that he will be married to a wife with some type of FGM/C who has not had any partnered sexual experience (especially involving vaginal penetration). Comprehensive information should be given on the nature of the procedure, expressing clearly that the procedure does not involve the hymen or penetration into the vaginal canal and that de-infibulation alone has no bearing whatsoever on whether one has had partnered sexual activity, whatever the symbolic significance of that fact may be in the relevant culture [6].

Other types of FGM/C with complications, such as painful or inflamed vulvar epidermal cysts, scarring, or adhesions, do not always need surgical treatment. There is no conclusive evidence as to the benefit of clitoral reconstruction/re-exposure surgery in adult women with FGM/C and there is no evidence of benefits or risks/harms of clitoral surgery performed before sexual debut [16, 25]. We believe that clitoral reconstruction should never be performed on minors.

For most girls living in a high-income country with access to full medical care who do not have Type III FGM/C, the potential morbidity and mortality associated with future pregnancy and childbirth will not be substantially different from that faced by their peers who have not undergone genital modification, with the possible exception (depending on the type of FGM/C) of a higher risk for perineal tears and episiotomy [31].

The psychological impact on a child of having their genitalia cut is difficult to study scientifically (i.e., isolating causes due to the cutting as opposed to other factors), and there is little to no good-quality evidence to support generalizations in this area [32, 33]. Nevertheless, a wide range of outcomes are possible, depending on the type and timing of the cutting (and hence the age or maturity of the child); how it was carried out and the context in which it was performed; what the child's beliefs, attitudes, or expectations were toward the cutting before, during, and after; and how the cutting is framed or interpreted in the child's community [34]. Some children, for example, may feel proud of having been included in an ancestral tradition, or having fulfilled a culturally significant initiation rite along with others in their peer group; others, by contrast, may experience the cutting as traumatic, violent, involuntary, and/or an infringement on their sexual and bodily integrity, with severely negative consequences (e.g., flashbacks and nightmares have been reported [29]). Again, it is important not to cause iatrogenic harm by assuming that the child feels traumatized or by making the child feel like a victim if that is not how they interpret the cutting themselves. Input from a child psychologist or psychotherapist experienced in working with children with FGM/C and their families should be sought, but may not be available in all settings [16, 33, 35, 36].

1.5.2 Legal Proceedings

If FGM/C is confirmed, an evaluation by legal authorities and child protective social service agencies might be ongoing to determine the legality of the procedure and the potential criminal charges (e.g., if there is evidence that the child was taken abroad to undergo FGM/C). FGM/C is illegal in most countries although the details and implementation of the legislation can vary [37]. If FGM/C was performed before the child entered the country where the examination is taking place, then criminal proceedings will generally not follow. There are sometimes exceptions to this; in a 2018 Swiss case, a mother was charged for having her two daughters cut in Somalia before leaving for Europe [38]. This legal decision was criticized as judicial overreach by both the Swiss Network against Female Circumcision and the Swiss Human Rights Institutions [39].

1.5.3 Medical Confirmation in the Framework of an Asylum Claim

FGM/C is considered a form of violence against women and girls and is a violation of human rights law: as such, FGM/C or risk of future FGM/C can serve as a basis for asylum in many receiving countries and can be used as the right to protection per the Geneva Convention [40, 41]. Some families who flee their countries, in part to seek protection for their daughters, can be asked to provide proof (via medical certificates) that the mother has undergone FGM/C and her daughter(s) have not and are therefore at risk of undergoing the procedure if forced to return to their country of origin.

Providing a certificate or affidavit attesting to the presence or absence of FGM/C should be seen as an opportunity to discuss the topic of FGM/C with the girl and her mother, and her father, to screen for potential, current, or eventual complications and to offer treatment, if necessary. Also, it is an opportunity to convey information on health and to raise awareness about other important issues such as hygiene, pubertal development, and sexual health. Adolescents may have questions about their menstruation or first sexual contact. Many children do not know why they left their country (if FGM/C is the main reason), so the conversation can serve to explain the reason for family migration, to raise awareness about the practice of FGM/C, including potential medical and legal complications and risks, and to convey preventive measures. It is also an opportunity to reassure the I/C/YP about their health, specifically around the appearance of their external genitalia to help them not to feel embarrassed about their vulva and to answer any questions that may arise. The certificate should include the medical history of the girl together with a detailed description of the genitalia, the FGM/C type and subtype according to WHO classification.

1.6 When FGM/C Is Not Identified

It is important to understand that in countries where there are laws dictating examination of girls from countries where FGM/C is practiced, a significant proportion of children referred with suspected FGM/C will have no evidence of FGM/C [17]. These children fall into two groups;

• *No physical evidence of FGM/C but risk factors for FGM/C are present.* Children may be referred because FGM/C is diagnosed in an older sibling (often performed before entry to a high-income country) or in another close family member. The clinical visit can provide an ideal opportunity for health and preventive information. Information and ongoing support can also be provided by connecting families to local peer support groups, if available.

An authoritative source of information, a risk assessment tool, and a "preventive compromise" (a document provided before traveling to the native country in which parents corroborate to prohibit their daughter from undergoing FGM/C and that can be shown to other family members) can be found in some countries such as Belgium and Spain [42, 43].

1 Assessing the Infant/Child/Young Person with Suspected FGM/C

• No physical evidence of FGM/C and no risk factors for FGM/C are present. In countries where there are laws dictating examination of I/C/YP from countries where FGM/C is practiced, many referrals for suspected FGM/C are appropriate. In contrast, some are referred inappropriately, which can include anonymous and malicious referrals, or referrals based simply on racial profiling [44]. Referrals may come from a nursery (daycare) or other childcare workers who notice an apparent abnormality when changing the child's nappy (diaper) and immediately attribute this to FGM/C because of the ethnicity or migration status of the child. Genital anomalies may be due to anatomical or congenital variations or due to common conditions such as labial adhesions or lichen sclerosus (Fig. 3.8 of chapter "Pictures with Potential Differential Diagnosis of FGM/C"). In addition, HCPs with inadequate training on FGM/C diagnosis and some caretakers may refer children from communities that generally do not practice FGM/C and thus have no known risk of FGM/C. These referrals may lead to significant psychological stress and stigma for families. The long-term impact of such referrals is unknown. Fear, shame, inadequacy, stigma, and resentment after an inappropriate referral may impact individuals, families, and entire communities, with potentially multiple negative social consequences [45].

1.6.1 The Need for Cultural Sensitivity and Risks of Stigmatization

In all cases where I/C/YP have their external genitalia examined, whether at annual physical examinations, medical asylum examinations, if there are genitourinary complaints, or if residing in a country where the law dictates such examinations to occur in at-risk I/C/YP, it is essential to acknowledge the possibility of causing fear and stigmatization in the child, her family, and/or the larger community. Such examinations should not be undertaken without the acknowledgment that if only performed on subpopulations with risk factors for FGM/C, this stigmatization will more likely occur. As such, and given that there are many physical findings that may be identified on routine examination of the external genitalia at annual physical examinations, it is recommended that external physical examination of the external genitalia be incorporated into well child visits of all girls.

1.7 Conclusion

An external genital inspection is an essential component of the assessment of all I/C/YP, including those with suspected FGM/C. Examining children with suspected FGM/C may be a requirement in some countries for medical-legal reasons and can be performed by designated specialists. The signs of FGM/C can be very subtle and

the examiner must be trained to identify a wide range of normal pre and postpubertal genitalia (both "cut" and unmodified) and must be familiar with the WHO definitions of FGM/C types and subtypes. Examiners must be familiar with the complications of the procedure and the differential diagnosis associated with the clinical findings. The relatively small number of girls affected by FGM/C in highincome countries presenting for medical evaluation can make it difficult for clinicians to develop adequate skills and competencies and to gain expertise. The adoption of routine pediatric genital examination of girls at well-child visits would help to develop general experience and expertise in identifying unaltered prepubertal and pubertal external genitalia, variations in findings, and clinical diagnoses of significance. Expert review and second opinion services can support learning and enhance the accuracy of the evaluation and determination of the findings. We hope this atlas will enhance HCP confidence in identifying and diagnosing FGM/C types and subtypes in children and adolescents.

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