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# **Genital mutilation of girls in Sudan**

## **Community- and hospital-based studies on female genital cutting and its sequelae**

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# ABSTRACT

**Background:** In spite of many decades of campaigns, female genital mutilation (FGM) is still highly prevalent in Sudan. One reason for this might be that campaigns have failed to approach fundamental values of FGM. In the absence of previous paediatric research on FGM, immediate and long-term complications for girls are basically unknown, as is their clinical picture.

**Methods:** Interviews were carried out according to questionnaires with open answers with 119 randomly selected respondents (30 young mothers, 29 young fathers, 30 grandmothers and 30 grandfathers) in a village in the Gezira in Sudan. To investigate adverse health effects on the child, 255 consecutive girls aged 4–9 years presenting to the Children's Emergency Hospital, Khartoum, were recruited. A detailed history was obtained and full examination, including inspection of genitalia, and investigations were performed to diagnose urinary tract infection (UTI). To investigate the association between FGM and primary infertility we performed a case-referent study. Cases were 99 women with primary infertility, among whom hormonal and iatrogenic causes, as well as male factor infertility were excluded. Cases underwent diagnostic laparoscopy. Referents were 180 primigravidae women recruited from antenatal care.

**Results:** While all female respondents in the village had undergone FGM, 44% of the young respondents had decided not to let their daughters undergo it. This change of practice was confirmed by the clinical study where 22% of the girls had undergone FGM, but a large share of the rest would have FGM later, leaving 26% of the girls allegedly without FGM in the future. The form of FGM was under-reported in an anatomical sense, 39% of forms being reported as "Sunna", extending to the labia majora. For girls under the age of 7 there was a significant association between FGM and suspected UTI. Symptoms from the urogenital tract in girls were heavily under-reported. Tradition and social pressure were the main motives for performing FGM. Religious belief, education level and socio-economic status significantly affected to what extent FGM was practised. Sexuality was an important aspect, mentioned as a motive both for and against FGM. Reinfibulation was widely practised in this area, with the main motive being sexual satisfaction of the husband. This was contradicted by the fact that male complications resulting from FGM, such as difficulty in penetration, wounds/infections on the penis and psychological problems were described by a majority of the men. Most of the young men would have preferred to marry a woman without FGM. Consequently, young fathers were more involved in the decision process when decisions were taken not to perform FGM. After controlling for age, education, socio-economy, and sexually transmitted infections, cases with primary infertility had a significantly higher risk than referents of having undergone the most extensive form of FGM involving labia majora (OR 4.69; 95% CI 1.49, 19.7). The anatomical extent of FGM, rather than whether or not the vulva had been sutured/closed, was associated with primary infertility.

**Interpretation:** There seems to be a trend towards abandonment and/or milder forms of FGM in Sudan, but a majority of girls still undergo severe forms of the practice. The validity of reported form of FGM is low. Genital mutilation contributes significantly to morbidity already in childhood, but a large share of this does not come to medical attention. By exposing male complications of FGM, showing male negative attitudes towards the practice, male and female sexual problems related to FGM and that FGM is a likely cause of infertility, the results challenge the most important marriage-related traditional motives for FGM. Traditionally FGM was performed to increase the chances of future marriage. Our findings, on the contrary, indicate that genital mutilation of girls might have an opposite effect by destabilising marriages through its effect on sexual and reproductive health.

إرضاء الزوج جنسياً كان هو الدافع الأساسي وراء انتشار ممارسة العدل بالمنطقة، في حين يعارض ذلك حقيقة شكوى أغلبية الرجال في الدراسة من مضاعفات سببها ختان الإناث، كصعوبة الإيلاج، جروح والتهابات القضيب بالإضافة إلى المشاكل و المضاعفات النفسية. وجدت الدراسة أن معظم الشباب كانوا يفضلون الزواج من امرأة غير مختونة و من ثم كان الآباء الشباب أكثر تدخلاً في عملية إتخاذ القرار خصوصاً فيما يتعلق بالختان. بعد التحكم بعوامل السن، التعليم، المستوى الاجتماعي و الإقتصادي و الأمراض المنقولة جنسياً ، إتضح بصورة واضحة أن النساء المصابات بالعقم الإبتدائي لهن إحصائية أعلى من الحالات المرجعية لأن يكن قد تعرضن لأشد أشكال الختان حدة و الذي يشمل الشفرين الكبيرين. كما بينت الدراسة وجود علاقة العقم الإبتدائي بالمدى التشريحي للختان عوضاً عن حجم فتحة المهبل سواء كانت مضيقة أو مخاطة.

### التفسير :

يبدو أن هنالك ميل نحو ترك أو تخفيف حدة الختان بالسودان ، و لكن و بالرغم من ذلك لا تزال أغلبية كبيرة من الفتيات تتعرض للأشكال الأعنف و الأشد حدة للختان. مصداقية نوع الختان المبلغ عنه ضئيلة. يلعب الختان دوراً هاماً في الإصابة بالأمراض في مرحلة الطفولة و لكن جزء كبير من هذه الحالات المرضية لا ترقى لتلقى إهتماماً طبياً. بالكشف عن المضاعفات الذكورية لختان الإناث و توضيح الموقف السلبي المعارض للذكور تجاه هذه الممارسة، و المشاكل الجنسية لدى النساء و الرجال المرتبطة بختان الإناث و حقيقة أن ختان الإناث هو من الأسباب المهمة المؤدية للعقم، تعد هذه النتائج تحدي لأهم الدوافع التقليدية وراء هذه الممارسة و المتعلقة بالزواج، حيث كان ختان الإناث يمارس لزيادة فرص الزواج المستقبلية. نتأجنا على النقيض بينت أن ختان الإناث قد يكون له أثر عكسي على استقرار الزواج من خلال آثاره على الصحة الجنسية و التناسلية.

لارس المروث  
إستوكهولم 2005

## ABSTRACT IN ARABIC

### ملخص:

### خلفية:

بالرغم من الحملات الممتدة على مدى عدة عقود، ما يزال ختان الإناث يمارس بصورة واسعة النطاق في السودان، لعل أحد أسباب ذلك يرجع الى فشل هذه الحملات في فهم و إدراك القيم الجوهرية خلف ممارسة ختان الإناث. و في ظل غياب البحوث التي تدرس ختان الإناث خلال مرحلة الطفولة ظلت الصورة الإكلينيكية، المضاعفات الآنية و بعيدة الأجل عند الفتيات غير معروفة أساساً.

### منهاج البحث:

تمت مقابلة 119 شخص بقرية بالجزيرة في السودان ، تم إختيارهم عشوائياً بإعتماد إستبيانات ذات أسئلة مفتوحة (30 أم شابة، 29 أب شاب، 30 جدة، 30 جد) لفحص الآثار المرضية غير المرغوبة للختان على صحة الفتيات تمت دراسة 255 حالة لفتيات تتراوح أعمارهن بين 4 - 9 سنوات لدى مراجعتن لحوادث مستشفى حوادث الأطفال بالخرطوم، حيث تم التحصل على تاريخ مرضي مفصل لكل حالة بالإضافة الى فحص طبي كامل يشمل معاينة الأعضاء التناسلية و الفحوصات المخبرية لفحص إلتهاب المجرى البولي التناسلي. و لدراسة العلاقة بين ختان الإناث و العقم الإبتدائي عند النساء قمنا بإجراء دراسة مرجعية درست فيها 99 حالة لنساء يعانين من عقم إبتدائي بإستبعاد حالات العقم الناتجة عن خلل هرموني أو تلك الناتجة عن أسباب طبية أو مسببات ذكورية ، خضعت كل الحالات المدروسة لفحص منطاري تشخيصي، في حين تم إعتبار 180 امرأة في حملهن الأول شاركن طوعاً في الدراسة أثناء مراجعتن لعيادة متابعة الحمل كحالات مرجعية مقارنة.

### النتائج:

في حين كانت كل النساء المشاركات في البحث بالقرية مختونات، 44% من الأمهات الشابات في الدراسة كن قد قررن عدم تختين بناتهن. هذا التغيير في الممارسة أكدته الدراسة الإكلينيكية، حيث بينت أن 22% من الفتيات قد تم ختانهن مع رغبة جزء كبير من النسبة المتبقية في ختان بناتهن في المستقبل ، تاركين بذلك 26% من الفتيات تحت الدراسة بدون احتمالية ختان مستقبلاً. لوحظ من خلال الدراسة عدم مصداقية شكل الختان المبلغ عنه و بالأخص من الناحية التشريحية حيث أن 39% من حالات الختان المبلغ عنه كختان (سني) تمتد في الواقع للشفرين الكبيرين. في حالة الفتيات أصغر من سن السابعة ، توجد علاقة دالة بين الختان و احتمالية الإصابة بإلتهاب المجرى البولي التناسلي. التقاليد و الضغوط الإجتماعية هي الدوافع الأساسية وراء ممارسة ختان الإناث. المعتقدات الدينية ، التعليم، الوضع الإقتصادي و الإجتماعي لها تأثير عام على مدى ممارسة ختان الإناث. يعتبر الجنس مؤثراً هاماً للمؤيدين و المعارضين لختان الإناث على حد سواء.

# LIST OF PUBLICATIONS

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals. All papers are presented in full in the Appendix.

- I. **Almroth L**, Almroth-Berggren V, Hassanein OM, El Hadi N, Al-Said SS, Hasan SS, Lithell U-B, Bergström S.  
A community based study on the change of practice of female genital mutilation in a Sudanese village  
Int J Gynaecol Obstet, 2001. 74(2): p. 179–85
- II. **Almroth L**, Almroth-Berggren V, Hassanein OM, Al-Said SS, Hasan SS, Lithell, U-B, Bergström S.  
Male complications of female genital mutilation  
Soc Sci Med, 2001. 53(11): p. 1455–60
- III. Almroth-Berggren V, **Almroth L**, Hassanein OM, El Hadi N, Lithell U-B, Bergström S.  
Re-infibulation among women in a rural area in central Sudan  
Health Care Women Int, 2001. 22(8): p. 711–722
- IV. **Almroth L**, Satti A, Bedri H, El Musharaf S, Idris T, Hashim M SIR K, Suliman GI, Bergström S.  
Urogenital complications among girls with genital mutilation. A hospital-based study in Khartoum.  
Accepted for publication, Afr J Reprod Health
- V. **Almroth L**, El Musharaf S, El Hadi N, Obeid AR, El Sheikh MA, El Fadil SM, Bergström S  
Primary infertility after genital mutilation in girlhood: is there an association?  
Accepted for publication, Lancet

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## ABBREVIATIONS

CI	Confidence Interval
DHS	Demographic and Health Survey
FGC	Female Genital Cutting
FGM	Female Genital Mutilation
HSG	Hysterosalpingography
IFMSA	International Federation of Medical Students' Associations
n.s.	not significant
NGO	Non-Governmental Organisation
OR	Odds Ratio
SD	Sudanese Dinars
SNCTP	Sudan National Committee on Traditional Practices affecting the health of women and children
STI	Sexually Transmitted Infections
SVCP	Sudan Village Concept Project
UNICEF	United Nations Children's Fund
USD	USA dollar
UTI	Urinary Tract Infection
WHO	World Health Organization

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## Prologue

I first came into contact with genital mutilation of girls during medical school in 1995 when I did a clinical attachment in Asmara, Eritrea. I remember how difficult it was to recognise the anatomy, but also that doctors and nurses took hardly any notice of the practice. It was taken for granted that girls had undergone the procedure, and it was generally not discussed with the parents. Being ignorant about the issue, and afraid of cultural pitfalls, I was reluctant to ask about the practice, and perhaps I even thought it was not my business as a foreigner. After returning to Sweden it did not take long until I met immigrant girls and women with female genital mutilation (FGM), and I soon realised that it was wrong to keep the subject at a distance. It was actually, my business, my responsibility, to learn about FGM in order to give better medical care.

When I started to work with the student-run development project Sudan Village Concept Project (SVCP), which is described in more detail later, I came into contact with FGM again. The subject was often discussed, as it was an issue that was unknown and strange to the multinational team working with the project, and was difficult to understand and prepare oneself for. Interestingly, the development project often provided the first opportunity to learn about FGM for the Sudanese participants as well. Due to the complexity of the subject, and the concern of adverse effects if we launched a campaign that did not fit the situation in the villages, we first wanted to find out the villagers' knowledge of, attitudes towards, and practice of FGM. This is the basis of the first three papers of this thesis.

The SVCP and the interviews of the first phase of the research brought us close to the villagers. We got to know many different people, and became close friends with some. The stories and lived experiences we got to know validated our quantitative data, but also made us realise that there are probably unmet needs in medical care, especially for girls. The students working in the SVCP, including me, graduated and started to work clinically as doctors, many of them in paediatrics. It seemed as if the problems related to genital mutilation of girls, which we had learned about before, were not present at the hospitals. This was hard to believe, considering the severity of the complications we had learned about. About 2000 girls under 15 years in Sweden were born in countries where most girls undergo FGM. I work in paediatrics, but I dare say that few of my Swedish colleagues would reflect on FGM as a possible cause of morbidity in these girls. What is even more surprising is that I learned from my Sudanese colleagues in paediatrics that the same would be true there. Thus we decided to probe into the FGM-related morbidity in girls (paper IV). In the absence of previous research on girls, we decided to start where we were standing, in the paediatric casualty, being fully aware of the limited part of the whole that would be visible there.

By probing into the practice by interviews in the village, we learnt more about many different aspects, which was essential for the coming intervention in the village by the SVCP, but it also struck us how unexplored some very fundamental aspects of the practice are. The role of men, different aspects of sexuality, and, not least, fertility seemed to be very central to the practice of FGM, but there was little to read about these things in the literature. There was also a theoretical possibility that the FGM-related infections in girls we heard about in the village could be related to infertility. Thus the study on the possible association between FGM and infertility followed (paper V).

Research should never be undertaken for its own sake. It is important to direct the efforts to areas where the results could add important knowledge and understanding, which eventually, in the long run, could lead to the abolition of FGM or improved health for girls or women. The studies contained in this thesis are an attempt to achieve this, by focusing on two areas: FGM in the context of marriage and reproduction and genital mutilation from the girls' perspective.

# 1. Introduction

## 1.1 Background

About 2 million girls undergo genital mutilation every year, and more than 130 million currently living girls and women have experienced the mutilating operation (1). Sudan is one of the countries where female genital mutilation (FGM) is highly prevalent, also in its most severe forms. There were attempts to counteract the practice in Sudan back in the 1920s, and legislation against the severest form was introduced in 1946, even though it was not enforced (2). Research about FGM has a long history in Sudan, where doctors were active already in the 1960s (3, 4). However, it was not until the 1970s that anti-FGM work gained momentum in Sudan. In 1975 the Sudan Family Planning Association, and in 1977 the Sudanese Society of Obstetrics and Gynaecology adopted recommendations aiming at abolishing FGM (2). Non-governmental associations with the same aim soon followed with the formation of Babiker Badri Scientific Association for Women's Studies in 1979 (5) and the Sudan National Committee on Traditional Practices in 1985 (6). Today several governmental and non-governmental organisations work to various extents with programmes against FGM. Sudan served as an arena to bring the subject up to an international level at an early stage. WHO arranged the first international conference on FGM in Khartoum in 1979 (7), and other conferences with an African perspective followed (8).

In spite all the efforts FGM is widely prevalent in Sudan and other countries where it has traditionally been practised, but there might be a change in progress. FGM has been addressed from many aspects: as a public health problem (9), as a cause of medical complications (10), from ethical aspects in health care (11, 12), from human rights perspectives (12), from gender perspectives (13) and from legal aspects (14). FGM is a complex area, and the key to abolition is not to be found in only one field. We do, however, believe that the medical field can make an important contribution by providing facts for valid arguments, improving health care for girls and women and, not least, mobilising people and putting FGM on the agenda.

This thesis will be presented in the academic discipline "International Health", which has its focus on health problems that are common in low-income countries but uncommon in Sweden. The subjects of the different papers range from anatomy and microbiology to public health and social sciences. Consequently, it has been important to form multidisciplinary teams, in which knowledge representing different fields made it possible to design the studies properly, but also to interpret the data from different aspects. In the different studies social scientists, public health scientists, gynaecologists, obstetricians, paediatricians, microbiologists, medical students, newly graduated medical doctors and a statistician have been involved in design, data collection and analysis. Efforts were made to

form teams that could achieve a global approach, not only from professional perspectives, but also from gender and cultural perspectives. I initiated the research and came up with the original ideas and hypotheses, except for paper 3 where Vanja Berggren did that. My main role in the research process was, however, to coordinate the teams, so that all members' detailed knowledge was made use of. To be able to do this I had to broaden my knowledge base outside my own field, into the fields of qualitative methodology, social sciences and obstetrics and gynaecology in poor settings, through courses and field studies.

This thesis will focus on the girl child and the role of men/marriage/fertility in relation to genital mutilation of girls, in order to approach fundamental values of, and motives for, the practice.

## **1.2 Female genital mutilation**

### *Definitions*

A WHO classification (15) recognises four degrees of FGM (Table 1). This classification may give the false impression of anatomically distinct forms. In reality, the practice varies widely, not only regionally, but also locally between different practitioners. The WHO classification defines all forms where the sides are stitched together, be it the remnants of labia minora or majora, and regardless of the extent of stitching, as type III. Thus it is not possible to judge the anatomical extent of the FGM operation from the WHO classification.

The age at which FGM is performed varies greatly between different ethnic groups. It can be performed from infancy to late adolescence, but is predominantly performed on girls between 4 and 10 years of age (1).

Many communities use local terms for the practice. The most severe form, infibulation, is also known as "Pharaonic circumcision" in Sudan and "Sudanese circumcision" in Egypt

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**Table 1.** The WHO classification of female genital mutilation (15)

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Type I	Excision of the prepuce and part or all of the clitoris.
Type II	Excision of the prepuce and clitoris together with partial or total excision of the labia minora.
Type III	Infibulation. Excision of part or all of the external genitalia and stitching/narrowing of the vaginal opening.
Type IV	Pricking, piercing, incision, stretching, scraping or other harming procedures on clitoris and or labia.

---

(3, 15). A modified, less extensive, form of infibulation has been called “intermediate circumcision” (16-18), “type 2” (19) or “matwasat” (18, 19) in Sudan. It is important to note that all these terms correspond to WHO type III forms of FGM. “Excision” is another term sometimes mentioned in the literature (2-4, 17, 20). This could correspond to either WHO type I or II, depending on whether only the clitoris is removed or the labia minora as well.

A secondary form of FGM is reinfibulation, performed on infibulated women who have given birth, are widowed or divorced, to recreate the narrow vulva of a virgin (17, 21, 22). Women who have undergone infibulation have to be deinfibulated (cut open) to allow childbirth. After deinfibulation the raw, bleeding edges must be secured in some way. Two options are available (9). The first, a circular stitching around the remnants of the labia majora, leaves the vulval area open, allowing the free flow of urine and menstrual blood. The second option is the one traditionally performed and is considered a reinfibulation. The raw edges are sewn back together to restructure the hood of skin covering the urethra and vaginal introitus. This is a medically unnecessary practice. The definition of “reinfibulation” is not always clear. It should, however, be distinguished from the episiotomy repair, aiming at reconstructing a normal vulva anatomy postpartum. The need for a more extensive tightening beyond episiotomy repair is the basis of the reinfibulation practice and its potentially adverse health effects.

### *Terminology*

There is controversy about the terminology of the practice. The term “mutilation” is medically correct, since it comprises the removal of normal, healthy organs without any medical indication. However, this term also carries a condemnatory attitude, which is possibly offensive to some groups, including women who have undergone the procedure.

“Female circumcision”, the term that was traditionally used to describe the practices, is still in common use. This term is, however, problematic from many perspectives. Firstly, it implies an analogy with male circumcision, which is wrong both from anatomical and religious aspects. The procedures performed on female genitals are almost always more extensive than cutting the prepuce, as in men. Whereas there is religious authorisation in Judaism and Islam for male circumcision, there is no such religious recommendation for cutting female genitals (23). Secondly, there is confusion on its meaning. Circumcision has been used by some to only describe excision of the clitoral prepuce (2), while most have used it as a general term for all forms. Thirdly, the use of the term might indicate that there is a case for medicalisation (involvement of health professionals) in some types of procedures, which is not desirable (15).

Lately the term “female genital cutting” (FGC) has appeared in the literature. The term FGC, in my experience, is not generally known in Sudan. While it avoids the problematic

aspects of the other terms, it still fails to recognise the extent of what is actually taking place. The “cutting” taking place in infibulation would in males anatomically correspond to the *removal* of the glans, most of the penile tissue and the scrotal skin.

Female genital mutilation is the most widely used term to describe the practice in a scientific context. During 2004, the term FGM was five times more common than FGC in scientific articles indexed in Medline.

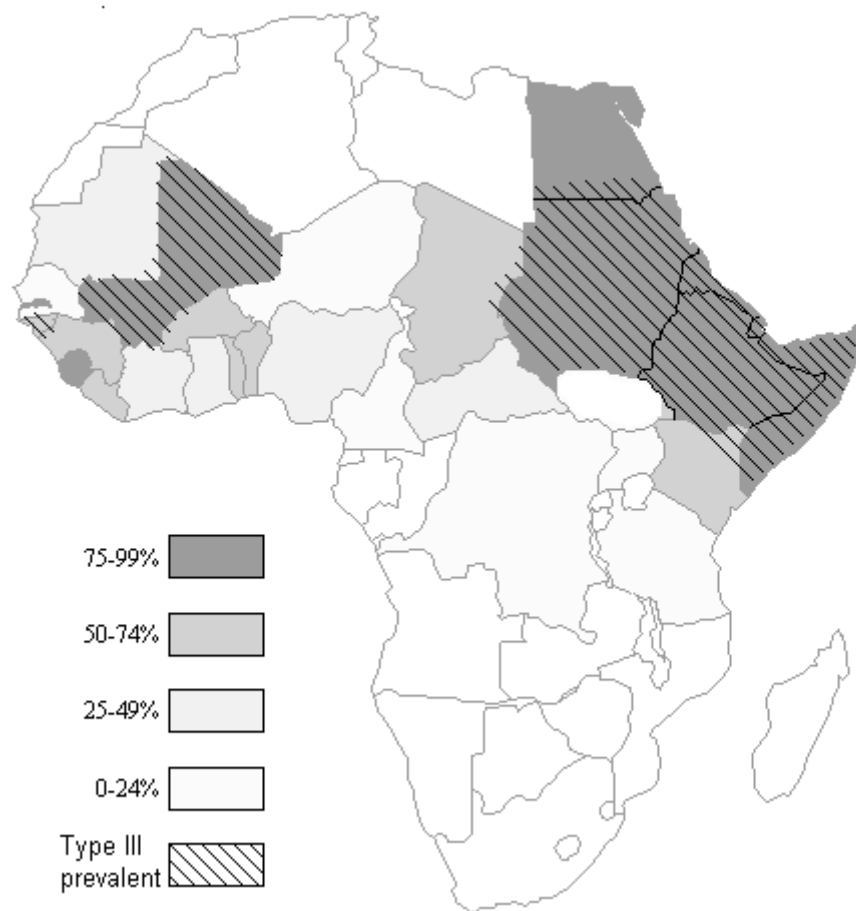
Consequently FGM and the international terminology stated by the WHO (15), is used throughout this thesis, but we recognise the possibly negative aspects of the term “mutilation”. For the actual fieldwork the colloquial Sudanese terms were used, especially for interviews. In the village the term “female genital mutilation” might have been understood as condemning the practice, which would not have been suitable or possible in an interview situation. Thus we consistently used the Sudanese Arabic terms, which are “Khifad” or the colloquial “Tahour” for female circumcision, “Gataa el bazr” or “Sunna” for clitoridectomy, “Khifad Firouni” (Pharaonic circumcision) for infibulation, “Tasheem” (decircumcision) for deinfibulation, and “Adal” (recircumcision) instead of reinfibulation. The Sudanese Arabic terms can sometimes have multiple meanings. “Tahour” is used both for male and female circumcision and literally means cleanliness, often understood as religious cleanliness. The word “Sunna” also has a religious value and meaning according to the tradition of Prophet Mohammed. In the context of FGM, “Sunna” sometimes implies only the cutting of the prepuce of the clitoris. The terms used by the villagers, with their own definitions, were translated into the international terminology.

### *Epidemiology*

FGM is practised mainly in north-east Africa, but also in some areas in western Africa (see Figure 1 for distribution in Africa), in southern parts of the Arabian peninsula, along the Persian Gulf, and among some migrants from these areas to Europe, North America and Australia (1). The fact that FGM is also common in south-east Asia, for instance in Malaysia (24) and Indonesia (25), has often been neglected. These countries are not included in the estimate of 132 million girls and women subjected to the practice (1).

About 90% of women in northern Sudan have undergone FGM, in most cases the most severe form, infibulation (18, 26). There is great variation inside Sudan. While in some areas almost all women have undergone severe forms of FGM, other areas show very low prevalence and/or milder forms (18, 19). In Sudan, infibulated women normally undergo reinfibulation after delivery (27). El-Dareer performed a survey of FGM in northern Sudan in 1982 (16, 26, 28). The results show that the community was in favour of the continuation of the practice, regardless of type. Those who were against the practice tended to be young





**Figure 1. The prevalence of female genital mutilation in Africa (1)**

and/or well educated (28). These findings were confirmed by the Sudan Demographic and Health Survey (DHS) 1989/1990 (18).

### *Sociocultural determinants*

Female genital mutilation is a very sensitive and complex subject. Medical, psychological, sexual, religious, cultural, social, economic, gender and human rights aspects, to mention a few, intertwine to a web that is difficult to understand and dissolve. Motives for performing FGM are often expressed as religious, though neither the Koran nor the Bible mentions it (23, 28, 29). Basically FGM expresses the perceived need to control women's sexuality and fertility (30). Female identity, tradition, hygiene and increased fertility (31), or future marriage (15, 32, 33) are often claimed to be motives for FGM. It has been stated that, in

most regions where FGM is practised, men may refuse to marry a woman who has not undergone FGM (32). FGM is here often seen as evidence of virginity and dignity. The tight introitus created by reinfibulation is thought to stimulate sexual satisfaction for the husband (9, 17). With the same purpose, to increase sexual satisfaction for the man, reinfibulation is sometimes combined with further tightening of the introitus to its virginal state (9). Sudanese researchers have stated that FGM in Sudan is perpetuated by women and approved by men as a means of controlling female sexuality (17). It is often believed that men prefer marrying women who have undergone FGM because the women would then not be sexually overactive and unfaithful (34).

### *Previous research about complications*

Complications of FGM have not been well elucidated in research. Findings about complications have mainly been based on self-reported problems by adult women, case reports or theoretical assumptions. There is a lack of clinical studies with control groups. As a result there is now controversy over the significance of some health effects. There have been reports of immediate complications (shock due to pain and/or haemorrhage; difficulty in passing urine; wound infection and damage to surrounding tissues), long-term health effects (repeated urinary tract infections; chronic pelvic infections; tight infibulation resulting in haematocolpos; difficulty of micturition; menstrual and sexual problems; vulvar abscesses; inclusion cysts; calculus formation; keloid formation and infertility), and of obstetric complications (perineal lacerations; consequences of deinfibulation including blood loss, injury to the bladder, urethra, or rectum and puerperal sepsis; delay in labour and its consequences, foetal loss and foetal brain damage, vesicovaginal and rectovaginal fistulae) (3, 9, 16, 35-37). The effects on mental and sexual health are even less known (35). The World Health Organization has made a systematic review of the health effects of FGM (10). This report lists studies reporting complications. It does not, however, critically analyse the findings from a scientific point of view, to find out whether methods, results and conclusion are scientifically correct. Obermeyer (38, 39) and Yount (40) have made attempts to critically analyse research findings about complications of FGM, and have found that few studies have been appropriately designed to measure these effects (39, 41).

There is also a lack of research on complications after reinfibulation. These may be severe, since it exposes the woman to a repeat risk of the tissue damage implicit in the first infibulation (17). The scar will also have to be reslit at subsequent deliveries. Multiparous women usually have heavily scarred and deformed perineums from repeat deinfibulations and reinfibulations (9).

Whereas there are many clinical studies available on the effects of FGM on adult women, especially from gynaecological or obstetric aspects, there are few on girls. To my

knowledge, there are only a couple of case series (42, 43), but no systematic analytical research. The same is true for possible male complications related to FGM.

### **1.3 The girl child**

#### *Normal child development and experience of trauma*

Genital mutilation of girls most often takes place somewhere between 4 and 12 years of age. This is an important period in life when both physiological and emotional development is rapid and sometimes decisive for the future. The subject is wide, and there is extensive knowledge, so the following is just a very brief introduction to the area.

As a preschooler the child explores emotional separation, alternating between strident opposition and close dependence. Increasing time spent in school and play with other children sets new demands for adapting to rules and relationships. Tension between the child's growing sense of autonomy and awareness of internal and external limitations is affected by, and in turn affects, development in many respects. Children often experience complicated feelings towards parents and other close persons: intense love, but also jealousy and resentment. Angry feelings towards parents can evoke fear of risk of abandonment. Curiosity about genitals and adult genital organs is normal, and interest in gender differences and sexual behaviour increases progressively till puberty (44).

Thus, FGM is performed in a sensitive period for the child, when she is developing her sense of identity in relation to others. The psychological and physical effects of genital mutilation in girls are basically unknown (1). For other forms of trauma in this age, researchers recognise that children's responses to major stress are similar to adults' (re-experiencing the event, avoidance, and arousal) and that these responses are not transient. Post-traumatic stress syndrome is the most common psychiatric disorder after traumatic experiences, including physical injuries. There is also evidence of other comorbid conditions, including mood, anxiety, sleep, conduct, learning, and attention problems (45). Child sexual abuse has long-term repercussions for adult mental health, parenting relationships and child adjustment in the succeeding generation (46). FGM is very different from other forms of traumatic experiences and sexual assault, since it is performed in a setting where there is strong belief in the positive effects of the practice. There are often festivities and the girl receives gifts. In spite of these alleged positive effects, considering the extent of the operation, the pain and other effects many girls face, it is likely that genital mutilation in girls has severe repercussions, not only for physical health, but also psychologically and developmentally.

### *Genital infections in girls*

Vulvo-vaginitis is inflammation of the vulva and vaginal tissues. In children, the vulva is usually inflamed first, with the vagina uninvolved, or secondarily affected. It is the most common gynaecologic disorder in girls (47, 48).

Pre-pubertal girls are particularly susceptible to vulvo-vaginitis, for both anatomical and physiological reasons. In girls there is a lack of the protective fat pads and pubic hair of adult women, and the vulvar skin is thin and sensitive. In the absence of adult levels of oestrogen, the vaginal mucosa is thin and atrophic, and the vagina has a neutral pH, but is warm and moist, which makes it an excellent culture medium (47-49). Inadequate cleansing of the vulva, irritants against the vulva, and foreign bodies are other risk factors for vulvo-vaginitis in girls (47). Discharge, discomfort, itching and urinary symptoms, odour and redness are the most common complaints (47).

Non-specific vaginitis accounts for the majority of cases of paediatric vulvo-vaginitis. This is caused by an alteration in the flora of the vagina, causing inflammation. Treatment is directed toward improved hygiene and avoidance of irritation (47). Bacterial overgrowth of staphylococci, streptococci, enterococci and *Escherichia Coli* requires specific antibiotic therapy.

Specific vaginitis is caused by candida, foreign body, chemical or allergic reactions or sexually transmitted infections (STI) (47). Each of these causes is rare in children, and therefore requires special considerations and investigations. In the case of STI, the possibility of sexual abuse should be considered.

### *Urinary tract infections in girls*

Urinary tract infections (UTI) in girls are the most common potentially serious bacterial infections in infants and young children (50). Symptomatic bacteriuria in infants occurs equally in both sexes, but after infancy in prepubertal children the incidence it is at least three to four times higher among girls (51). Infections of the urinary tract can be limited to the bladder (cystitis), or ascend to the upper collecting system (pyelitis), or renal parenchyma (pyelonephritis). Unique to UTI in children is the increased risk of renal parenchymal injury due to pyelonephritis, progressing to irreversible renal scarring with the consequences of hypertension, preeclampsia and chronic renal disease (50). Consequently it is essential to correctly differentiate site of infection. Recurrent UTI in girls is associated with renal damage (52).

*Escherichia coli* is the most common infecting organism, identified in approximately 80% of UTIs (53). Diagnosis of UTI may be suggested by a combination of signs and symptoms, but in children culture of the urine is the gold standard. The inevitable delay for culture

results justifies the use of tests that may predict the results of the urine culture. Urine dipsticks positive for leucocyte esterase and/or nitrite have shown high sensitivity and specificity (88% and 96% respectively) for diagnosing UTI in children in a meta-analysis (54), and 2+ for leucocyte esterase or positive nitrite has been suggested as strategy for presumptive treatment of UTI in children (55).

There are factors related to the child itself affecting the risk of acquiring UTI. *Dysfunctional voiding*, which is a condition of uncoordinated neurological control of the bladder and sphincter muscles, leading to inefficient bladder emptying and residual urine, elevated intravesical pressures and recurrent UTIs. This is an acquired condition, where the child enters a vicious circle (53). *Vesicourethral reflux* is not a likely cause of recurrent cystitis, but is responsible for recurrent episodes of pyelonephritis (53). *Labial adhesions* (see below) and *urethral strictures* are other predisposing factors for UTI in children. Urethral strictures are rare, and usually result from trauma. The female urethra is well protected from accidental trauma during childhood (56). Iatrogenic trauma, for instance during the FGM operation, might cause urethral stricture.

#### *Labial adhesions*

Spontaneous fusion of labia minora exists in about 2% of girls (57). The labia minora have a central line of adherence from an area immediately inferior to the clitoris, extending posteriorly to various degrees. It occurs most often in girls younger than 6 years, and is often asymptomatic (58). Labial adhesion is associated with local inflammation, and in the combination of the hypoestrogenic conditions of the prepubertal vulva, the condition might cause vulvo-vaginitis (58), asymptomatic bacteriuria (59) and recurrent UTIs (58, 60). After puberty, when the environment becomes more acidic, the condition usually resolves spontaneously, but it can be treated with topical oestrogen cream and, rarely, surgical separation of adhesions when indicated (58).

Theoretically, any form of FGM, where the two sides heal together to any degree, would be similar to labial adhesions as risk factor for vulvo-vaginitis, asymptomatic bacteriuria and recurrent UTI. There have, however, not been any studies on this.

## **1.4 Primary infertility**

### *Epidemiology*

Infertility, the inability for a couple to conceive, should be distinguished from other causes of childlessness, such as foetal wastage and child loss which contribute considerably to the problem in some parts of the world (61). Primary infertility refers to a couple who have

never managed to conceive, while secondary infertility refers to a couple who have previously achieved a pregnancy, but are unable to repeat this. Usually, at least one year of unprotected sex is set as the time to elapse to define the condition as infertility (62, 63), since 90% of normal couples conceive within the first year. However, another 5% will conceive within two years (61), so sometimes two years is used to define infertility (64). It has been estimated that around 50–80 million women and men worldwide are affected by infertility, many of them in poor countries (61, 65). Around 10–15% of couples worldwide are infertile according to the one-year definition (66). In Africa the number varies substantially from 10% to as much as one third in some areas (65, 67). Secondary infertility, rather than primary infertility, is the main childlessness problem in Africa (63, 65, 68). Higher prevalence of STIs and non-hygienic obstetric or abortion practices in Africa probably account for this difference (63). Primary infertility is estimated to be 3–5% in Sudan, and secondary infertility around 9–16% (68–70). Diagnoses of infertility in couples are found in the woman only in about 35%, in the man only in about 30%, and in both partners in about 20% of cases. In 15% of couples with infertility no cause can be found (66). Thus male infertility contributes to a substantial part of the problem, but this might not be recognised in an African setting (61, 71). Infertility has severe social implications, especially for the woman who often gets the blame, and risks divorce or her husband marrying another woman (67). However, the text below will focus on primary infertility in women, relating the problem to the subject of this thesis.

### *Primary infertility in women*

Ovulation is a prerequisite for conception. Ovulatory dysfunction usually shows clinically as abnormal cycle length and/or abnormal amount of menstrual loss. Ovulation is negatively affected by a variety of hormonal disturbances in the pituitary-gonad axis, but also by hyperprolactinemia, thyroid dysfunction and diabetes mellitus. Medical treatment may damage ovulatory function. Excessive physical exercise and rapid weight changes, as well as extremes in weight, also impact on ovulation (66).

Obstruction of the fallopian tubes and adnexal scar formation (adhesions) affect normal transportation of ova and spermatozoa, and are thus a cause of infertility even in the presence of normal ovulation. Tubal pathology is by far the most common cause of female infertility in Africa (63, 65, 72). Use of an intrauterine device and previous abdominal surgery suggest a predisposition to adhesion formation and increase the likelihood of tubal dysfunction (66), but the most common causes of tubal pathology are sequelae of infections by *Chlamydia trachomatis* and, less frequently, *Neisseria gonorrhoeae* (73). Gynaecological infections, especially chlamydia infection, can pass without any symptoms or signs (73), which makes medical history less reliable. A history of tuberculosis can be associated with tubal factor infertility (74, 75). The condition is relatively rare, and usually arises secondarily to a primary focus elsewhere (75). Schistosomiasis can give rise to tubal factor infertility, but can disturb function in all internal genital organs. Genital

schistosomiasis often coincides with urinary schistosomiasis. It is often associated with menstrual irregularities and symptoms from the lower abdomen (76).

Evaluation of tubal patency can be considered in a normal cycling woman with a partner where male factor infertility has been excluded (66). Hysterosalpingography (HSG) is usually performed to assess tubal patency. Retrograde pertubation under radiographic guidance will depict the uterine cavity and fallopian tubes. HSG has been found to have high false negative and high false positive rates (66, 77). Laparoscopy is a more invasive procedure, but allows not only testing tubal patency (by pertubation using methylene blue through the cervix while inspecting the fallopian tubes) but also identification of peritubal adhesions, endometriosis and pathognomonic changes of tuberculosis and schistosomiasis. Experiences from Africa show that there is a risk of underestimating the effect of tubal abnormalities if laparoscopy is not used (63, 77). Recent advances in ultrasound equipment have resulted in the application of ultrasound contrast sonography to detect tubal patency (73). This procedure, however, will not give information about other adnexal pathology.

#### *FGM as a cause of primary infertility*

The genital tissue damage provoked by FGM, with its inherent microbial contamination, creates a risk of vaginal infection. In the low oestrogenic environment of the pre-pubertal girl, the thin atrophic epithelium of the vagina may be susceptible to bacterial invasion. Such infections can be expected to thrive in the pre-pubertal girl's lack of vaginal acidity (47-49). In the absence of a protective environment, the infection might ascend to reach the uterus and the fallopian tubes, with risk of ensuing tubal damage and impaired fertility. This theoretical framework for FGM as a potential risk factor for primary infertility, with amendments based on our research findings, is outlined in Figure 4, page 61. The theoretical assumption that FGM might cause infertility is supported by clinical experience in Sudan (20, 37, 78) and Somalia (79). Pelvic inflammatory disease, PID, a well-known risk factor for infertility, has been said to be three times more common among women having undergone infibulation than among women having undergone clitoridectomy (3). In that particular study, however, selection and diagnostic criteria are not described, and there is no statistical analysis of the data. FGM has often been said to cause infertility, but until recently there has been little scientific support for this.

There have been several studies showing an association between FGM and urinary and genital tract infections in adults (80-83). All forms of vaginitis may include cervicitis, which leads to a change in cervical mucus pH (66). This, in turn, may have detrimental effect on the motility and ascent of sperm (66). Theoretically, FGM might cause infertility in this way as well.

The severe forms of FGM leave only a narrow opening for the passage of urine and menstrual blood. The narrow opening might be impossible to penetrate by sexual

intercourse. There are many stories about his problem in Sudan as a cause of primary infertility, but also reports in the scientific literature (84).

## ***1.5 Rationale for the studies***

In spite of many decades of campaigns and legislation, female genital mutilation is still highly prevalent in the areas where it has traditionally been practised. There may be many reasons for this, but one key issue might be that campaigns have failed to approach the fundamental values of FGM.

There are very few clinical studies or other systematic research on the primary victim of the practice: the girl child. In the absence of paediatric research on FGM, immediate and long-term complications for girls are basically unknown, as well as their clinical picture. Research findings would make it possible to improve health care for girls facing complications of genital mutilation, but might also reveal findings that challenge the perceived positive effects of the operation. If FGM is performed in order to increase future chances of marriage and ensure fertility, the risk of infections in the girl leading to infertility would be a significant argument against the operation.

Marriage, or future marriage, and sexuality are central in the context of FGM, and the practice is often seen as a symbol of decency, dignity and fertility. The fact that adult women are repeatedly subjected to genitally mutilating operations when they undergo reinfibulation shows the importance of FGM in this context. In marital life the female and male worlds converge in the context of FGM, and much of the fundamental motives for the continuation of the practice are found in this interaction.

One can argue over the necessity to perform further research about complications of harmful practices like FGM. After all, the main motives are not alleged health benefits, and it seems that previous campaigns focusing on health risks have had limited effect (30). Using the health risk approach alone has led to problems by overplaying the medical complications. Disbelief about the harmful effects of FGM could arise among women who have undergone the operation without such negative effects (12). In addition to this the health approach has tended to medicalise the practice (12, 30). However, the health risk approach is an important component of an integrated approach, also using social, cultural, religious, human rights, legal and women's empowerment approaches. Most of those who oppose the practice in Sudan use medical complications as arguments (18, 19, 28, 85). It is, however, often neglected in the debate that this ancient tradition also carries positive values for those practising it, and it is only when campaigns manage to address these perceived positive values that they can succeed. Further research is important to better argue against the fundamental motives for FGM and to use correct arguments in campaigns against the practice, avoiding dissonance between people's lived experiences and claims pronounced



by eradication campaigns. Information about health risks plays a role, but will not be enough to undermine a practice based on cultural beliefs and perceived need to control women's sexuality and fertility (30). Research about health risks related to these aspects of the practice would, however, add relevant information, which would be important for interventions focusing on social change.

## 2. Aims

The aim of this study was to investigate the practice of FGM in Sudan, both from a rural community-based perspective, and from an urban clinical hospital-based perspective, for girls and for women. In these two settings it aims at exploring FGM in the context of marriage and reproduction in order to identify factors influencing the practice of genital mutilation on girls. In addition to that, it explores possible short- and long-term sequelae of genital mutilation of girls.

Specifically, the objectives were:

- To determine what factors influence the practice of FGM among men and women of a young parental generation and a generation of grandparents (Paper I).
- To elucidate complications of and attitudes towards FGM among married men of the youngest parental generation, and among the generation of grandfathers in a rural area of Sudan (Paper II).
- To explore the practice of reinfibulation after childbirth and to outline the decision process concerning this practice (Paper III).
- To confirm or to reject two hypotheses concerning sequelae of genital mutilation in girls (Paper IV):
  - a) FGM has significant immediate adverse health effects on the girl child, and,
  - b) FGM is significantly associated with urinary tract infections in girls.
- To test the hypothesis that FGM during childhood causes ascending infections presenting as primary infertility in young women. Assuming that more extensive operations would have higher risks of infection, it is hypothesised that forms of FGM involving the labia majora are more strongly correlated to primary infertility than milder forms, and that forms of FGM where the two sides have been sutured together are more strongly correlated to primary infertility than other forms (Paper V).

### 3. Ethics

All research should be guided by ethical principles, all through the process from the planning phase. These ethical considerations are probably even more evident in issues concerning the genitals, and especially in sensitive subjects like FGM. Ethical clearance for the studies was received and the clinical studies were approved by ethics committees in the Children's Emergency Hospital, Khartoum, Sudan, at the Faculty of Medicine, University of Khartoum, Sudan, and at Karolinska Institutet, Sweden. However, some ethical aspects deserve to be commented on. Ethical considerations in research related to FGM have been outlined before from a sociological perspective (86). However, the Helsinki declaration of medical research ethics (87) has provided the guiding principles of our considerations, and its sections are referred to in brackets below.

Female genital mutilation is a sensitive subject with many social and sexual underpinnings, but it is also an important health problem. Research should be conducted only if the importance of the objective outweighs the inherent risks and burdens to the subject (§18) and it is likely that the populations will benefit from the results (§19). As explained above in the rationale, the research findings could provide valuable information for the prevention of the practice, but also for improvement of health care for girls and women. The study on girls is by its nature descriptive, and no more examinations were performed than would normally be the case. One can argue that inspection of genitalia is normally not done, which might be true, but in severely ill children presenting to the emergency ward, inspection of genitalia should be part of the routine examination in this age group. Otherwise important clinical findings might be missed. In this study, even patients with mild symptoms, which were not obviously related to the genitalia, were asked to participate. This was necessary, since it is not known what kind of symptoms could be related to FGM. Symptoms from the genital tract would rather be underreported, and symptoms from other parts of the body overemphasised. If the genitalia had not been inspected, this hidden morbidity could have been overlooked. For the study on infertility, there were no additional investigations than would normally be done. On the contrary, the research project supplied these women with investigations many of them could not have afforded themselves. By strict inclusion criteria for surgery (diagnostic laparoscopy) where we tried to exclude other causes than tubal factor infertility, we minimised the number of unnecessary surgical interventions.

In both studies we took precautions to safeguard the integrity of the girl or woman. All doctors collecting data received special training for this. For the study on girls, specially trained female Sudanese medical doctors did all clinical examinations and data collection. Examination, including inspection of genitalia, took place in a calm, secluded place with no other people present than the parents and the physician on duty. In this way we took precautions to respect the privacy of the subject, and the confidentiality of the information (§21).

Informed consent (§22), according to the texts available in the Appendix, was obtained orally from the guardian of the girl or from the woman for the two clinical studies. In health care there might always be a dependent relationship (§23) between the patient and doctor, perhaps even more so in our setting where the patient was often poor and poorly educated. We were well aware of this, and stressed the fact that participation was voluntary. In the study on infertility we provided expensive investigations for free for those participating. Poor women could possibly perceive this situation as meaning that they had no other choice but to participate. On the other hand, the reason for seeking medical care was to investigate the cause of their infertility. For the study on girls, patients not willing to participate in the study had the same procedures done as are normally the case at this hospital. Participating cases diagnosed as having UTI received treatment for free, even if they did not fully participate in all parts of the study. The fact that several patients chose not to participate in the studies indicates that we managed to inform about the right to abstain from participation.

Informed consent should preferably, but not mandatorily, be obtained in writing (§22). The respondents in our studies were most often poorly educated and some were illiterate. We deem it ethically inappropriate to ask for a written permission in such cases. They would not know what they were signing, and would probably have concerns whether this document could be used against them in any situation. Written informed consent in this context would only be in the interest of the doctor, to be able to show in case of complaints. Instead we chose a strategy of orally informing all respondents in colloquial Arabic according to the informed consent forms (see Appendix), and the consent was documented by the doctor.

Performing research in children leads to further ethical considerations. Children are vulnerable in several ways, which calls for special care in the design and implementation of research protocols (88). However, this does not justify exclusion of children from research (88). On the contrary, the relative lack of adequate medical research in children justifies more paediatrics-orientated research. It is inappropriate to extrapolate information from studies conducted in adults and generalise these findings to children (89). This is valid for diseases and drugs as well as for genital mutilation of girls.

To inspect genitals in girls, some of whom had undergone a possibly traumatic experience of genital mutilation, demands special precautions. It is important not to violate the integrity of the child, and not to expose the girl to another traumatic experience. Participating doctors had special training, and arrangements were done in the hospital setting to safeguard the integrity of the girl. Informed consent was obtained from the guardian of the girl, which is formally correct (§24), but the girl was also informed, in an appropriate way according to the age of the child, and was given the right to abstain (§25). In paediatric practice the term informed consent has been questioned, since only patients who have appropriate decisional capacity of their own can provide such consent concerning

themselves. In paediatrics the situation is different. Parents give their informed permission for diagnosis, treatment or research, with the assent of the child whenever appropriate (90). We believe the information given in our study to the girls and guardians managed to convey the message that participation was voluntary. Some guardians chose to not take part, and some girls refused participation in spite of their mothers' permission.

One ethical aspect that often does not get the attention it deserves is how results are dealt with. As researchers we have the obligation to disseminate the results, not only to the scientific community, but also to those whom they concern more directly (86). The results of the first three papers were presented at open meetings in the village where the interviews were conducted. These meetings were highly appreciated and had to be repeated at the request of the villagers. Thus, a forum for discussion of FGM was created, and the results were brought back to the participants. Links were also established to NGOs working against FGM in Sudan, such as SNCTP, Save the Children, UNICEF and Babiker Badri Association, with whom the results were shared. Seminars and workshops for the dissemination of the results of the other papers are planned to take place in Khartoum during 2005.

## **4. Settings in Sudan**

### ***4.1 The country***

Sudan is the largest country in Africa, with 2.5 million square kilometres, corresponding to almost one tenth of the size of Africa (Figure 2). It is a multi-ethnic country with diverse cultures and traditions. Located on the border of Arab and Sub-Saharan cultures, Sudan is characterised by two distinct cultural traditions. In the north the majority are Muslims, but there are also many Christians. Southern Sudan is dominated by Christianity and traditional religions. Many tribes in the southern part of the country have more in common with people in neighbouring countries than those in northern Sudan. There is a variety of local languages in Sudan, but Arabic is the official language and commonly spoken, at least in the north (18).

Sudan gained independence from British rule in 1956. With the exception of some years with democratic rule, the post-colonial time has been dominated by dictatorships, partly in combination with military rule, and the last two decades in combination with political Islam (91).

Sudan suffers from one of the longest lasting armed conflicts in Africa. Most of the post-colonial time has been marked by the civil war in the south, first from 1955 to 1972, then from 1983 to 2004 (91). The conflict has its origin in the struggle for independence for Christian-dominated southern provinces/ethnic groups from the Islam-dominated north, but other aspects, such as access to oil assets, have also been important (91). During the last few years peace negotiations seem to have been successful and recently a peace protocol was signed by the government and rebel groups from southern Sudan. During the last year, the conflict in Darfur has attracted international attention, and this is not included in the above-mentioned peace treaty. As a result of decades of civil war there are large groups of internal refugees, or displaced people, in Sudan, many of whom have sought refuge in the Khartoum area. This means people from all over Sudan are found in or around the capital.

The economy in Sudan is dominated by agriculture. During the last decade there have been large oil findings, and the petroleum industry is growing (91).

The population of Sudan is around 33 million, out of which, officially, about 5 million live in Khartoum, the capital (92). Illiteracy is a big problem, 60% of women and 34% of men being illiterate. School attendance for children aged 6–13 is 79% for boys and 77% for girls in urban areas, and 53% and 47% respectively in rural areas. For women the average age for the first marriage is 22 years in urban areas and 19 years in rural areas (92). The total fertility rate is approximately 5–6. Other health indicators also share features with other low income countries: the infant mortality rate is about 70 per 1,000 live births and the under-5

mortality rate around 100–125 per 1,000 live births (18, 92). The maternal mortality ratio is around 500–600 per 100,000 live births according to official statistics for northern Sudan (18, 92, 93), but the figures are uncertain and the true figure could reach 1,100 (93).

## **4.2 The village**

Data collection for Papers I–III was carried out in a village in the Gezira scheme along the Blue Nile in Sudan (Figure 2). Contacts with the villagers were made through a development project, the Sudan Village Concept Project (SVCP). This project had been working in villages in the Gezira scheme since 1994.

The SVCP was organised by Sudanese and Swedish medical students, under the umbrella of the International Federation of Medical Students' Associations, IFMSA (94). The project was located among a group of villages with about 25,000 inhabitants in Gezira State in the central region of Sudan. It focused on public health and prevention. There were three main principles: integration with the local community, inter-disciplinary co-operation and international involvement of students.

The preventive objectives concerned education on health and diseases, animal and agriculture, environmental health (latrines, water supply, malaria prevention etc.), vaccination programmes for man and animals and family planning. The curative objectives concerned activities such as construction and organisation of health units, sustainable drug supply, physical examination of school children etc. Veterinary and agricultural services were also established. There were special activities to guarantee sustainability, for instance health volunteers, women development centres and income-generating activities. Workshops were arranged regularly to keep organisations and authorities informed about the project and to provide an official forum for feedback from the community.

After all activities finished in the autumn of 1997 there were qualitative and quantitative evaluations. These showed that the project managed to achieve many of its goals, but also revealed some shortcomings (see Appendix for summary of achievements). One of the main assets for the project was the participating students. They were working for free, out of pure social and professional interest. Totally 36 students from 12 countries outside Sudan and more than twice the number of Sudanese students worked with the project. The local and international organising committees consisted only of students. Professional support and guidance needed was attained from the University of Khartoum, WHO, UNICEF and different NGOs. After this project there was a second SVCP outside El Faw in central Sudan.

The background to the research described in this thesis is to be found in the SVCP. The project had many activities concerning different aspects of health, but there was uncertainty as to how to address the subject of FGM. At the same time as there a need was felt to

address the problem, there was also a concern about the sensitivity of the subject, and the possible negative reaction of the villagers towards such activities. As a first step we thought it would be important to get to know the present position of the villagers in relation to FGM, and we decided to do a study on knowledge of, attitudes towards and practice of FGM before any intervention could start. Consequently, the study that now constitutes Papers I–III of the present thesis was presented to the villagers as an activity of the project.

Those who performed the study and who conducted the interviews were not completely new to the villagers. All Sudanese members of the team had been working with different activities of the development project before. My wife and co-researcher Vanja Berggren, and I had visited the village before, since I was the international coordinator of the SVCP. As a newly married couple, we were provided a house of our own, separate from the project house, and were introduced to, and took part in, the social life in the village. The social interaction in the village gave abundant qualitative information concerning family and marriage life. Women and men shared with us their opinions, thoughts and experiences, and were interested to listen to ours. The fact that the villagers knew who we were and knew that we were familiar with village customs and culture, probably facilitated data collection as well. They would not have told about personal problems related to FGM and sexual life to any stranger. The knowledge we gained from social life in the village goes very well in line with our findings from the interviews, which makes us confident in the validity of the findings.

As a part of the methodology the interviewers lived in the study village when the interviews were performed. This was possible only in one of the villages where the project owned a house. Hence this village constituted the basis of this study. According to the SVCP baseline survey there were about 3,600 inhabitants in the study village. It was estimated that 50% were below 15 years of age. Many of the male inhabitants did not live in the village at the time of the study. Lack of jobs made men move to cities to be able to earn enough money to support their families. This resulted in about 70% of the villagers being women. All inhabitants in the village were Muslims. Most of the families in the village had lived there since they settled in the 1920s. There were no displaced people or refugees in the village.

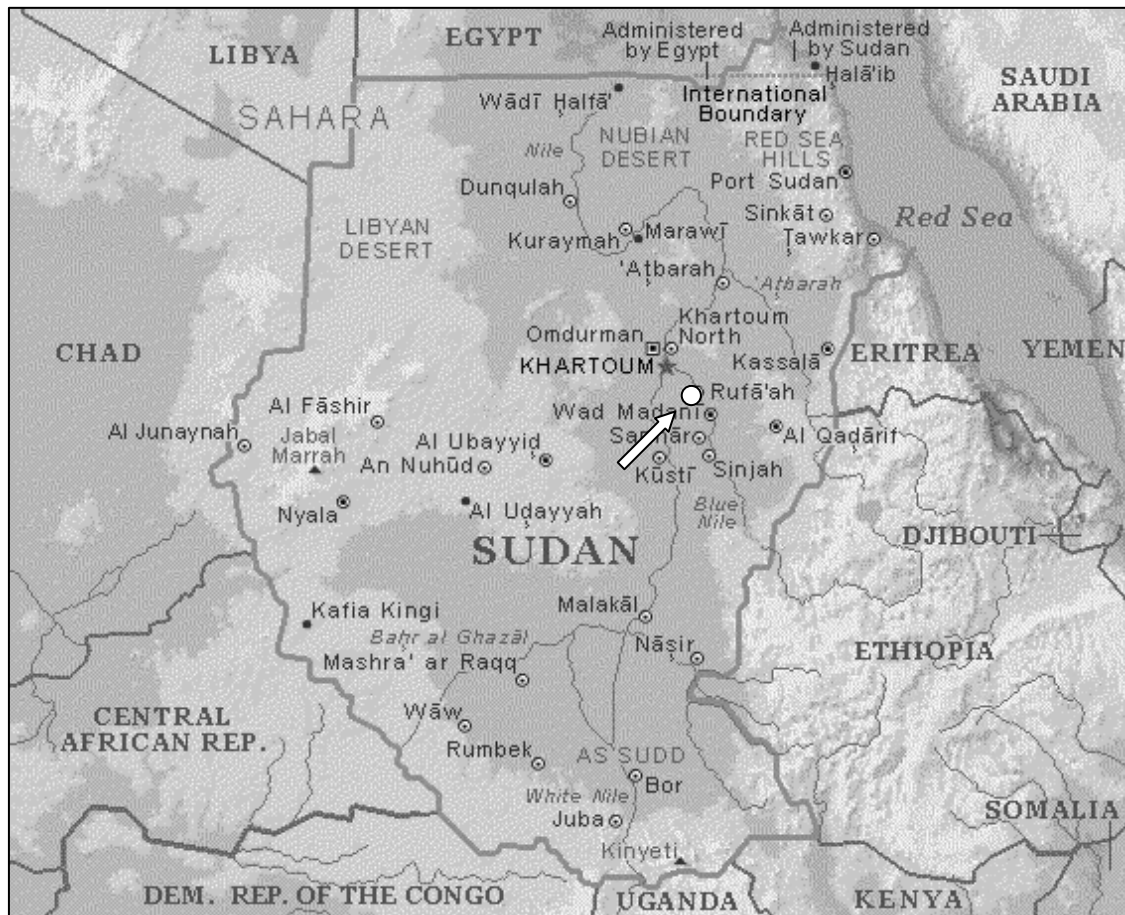
### ***4.3 The hospitals***

The study described in Paper IV was conducted in the Children's Emergency Hospital, which is a public, governmental, hospital. It is situated in central Khartoum, easily accessible by local transportation. Being a university hospital and well staffed, it is said to have a good reputation. In addition to this, it is, in practice, the only hospital in the Khartoum area where children get investigations, care and medications for free. This means that people from all over the capital and surrounding areas seek medical care there. The



emergency ward and other wards are run by registrars with the help of house officers (doctors in pre-registration training) under the supervision of specialists. People who can afford it tend to seek medical care in private clinics, where they meet senior specialists directly, avoiding the crowd and long waiting hours in the public hospital.

The study on infertility in relation to FGM (Paper V) was conducted in the department of Obstetrics and Gynaecology in Khartoum Teaching Hospital. Patients were recruited from two different referral clinics connected to the department; Fath Elrahman Elbashir Referral Clinic in central Khartoum, and Soba University Hospital referral clinic. Soba is situated in the southern outskirts of Khartoum, and thus receives not only patients from Khartoum, but also patients from the rural areas in Gezira south of the city. Both centres belong to the public health care system, but accept private patients on pay-for-service basis. The laparoscopies done for the study were all performed in Soba University Hospital in well equipped surgical theatres with modern laparoscopy equipment with television screens.



**Figure 2. Sudan with its neighbouring countries in North-East Africa. The setting for Papers I-III is indicated by an arrow.**

## 5. Subjects and methods

### 5.1 Papers I–III

Data for papers I, II and III were collected through interviews in a rural village in Sudan (see setting above). Methods, selection criteria and analysis described below apply to Papers I–III. In Paper I all interviews are included, in Paper II only interviews with men, and in Paper III only interviews with women.

#### *Preparatory work*

The questionnaires were tested on medical students in Khartoum before the start of data collection. The results and feedback attained were used to improve the questionnaires.

Contacts with the village were initially made through the development project Sudan Village Concept Project, which had been working in the village since 1994.

The election lists from 1996 were updated with the help of different villagers until no new individuals were added or withdrawn. In order to avoid selection bias, the respondents were randomly selected from these lists, except for the young men, as all men in the village fitting the criteria for group 2 were interviewed.

#### *Selection of respondents*

Four groups of villagers were interviewed:

1. married women 30 years of age and below;
2. married men 35 years of age and below, or older if their eldest daughter (or eldest son if they did not have a daughter) was less than 4 years old;
3. grandmothers;
4. grandfathers (the latter two groups irrespective of age).

The age limits for the different groups were established considering that people marry relatively late in this part of Sudan and that FGM is generally not performed before 5 years of age in this area. All those who were asked to be interviewed agreed except one elderly man. Three elderly women could not participate due to disease. Additional respondents were randomly chosen from the election lists to replace them. In total, 119 respondents were interviewed, 30 young women, 30 grandmothers, 29 young men and 30 grandfathers.

### *Interviews*

Interviews were carried out according to questionnaires with fixed questions with open answers (see Appendix). The answers were then categorised by the interviewers.

The interviews were carried out at the respondents' home between 25 March and 8 May 1997. Confidentiality was guaranteed before the start of each interview. There was no other person present at the time of the interview, except with some of the grandmothers who asked female friends to stay with them. The interviews were carried out in English and translated into Arabic. All interviews with men were carried out by Lars Almroth and a male translator. Three male Sudanese medical students translated. All interviews with women were carried out by Vanja Berggren and a female translator. All persons conducting interviews were known in the village from previous work in the development project.

### *Statistical analysis*

Significance testing of differences between proportions was conducted using the Chi-square test where applicable, with a value corresponding to  $p < 0.05$  for significance unless otherwise stated. Fisher's exact test was used when numbers were equal to or less than five.

## **5.2 Paper IV**

### *Patients*

The study was designed both to be a descriptive study of the clinical pattern of FGM among girls seeking emergency care, and to find out whether FGM is associated with urinary tract infections. The research team worked daytime in the emergency ward at the Children's Emergency Hospital Khartoum on selected days during the period March to August 2004. During this time all guardians of girls aged 4–9 years presenting to the emergency ward were asked for their informed consent to take part in the study. Out of 255 consecutive cases, who all accepted to take part in the general part of the study, 249 patients accepted full participation including inspection of genitalia. All patients constitute the study population for the descriptive part. For the second part about the possible relationship to UTI, this group was subdivided into cases with signs and symptoms of UTI and referents without such signs and symptoms.

Social and medical history was registered. The guardians, and the girl when appropriate, were asked about the FGM operation. A full examination, including inspection of genitalia, was performed on those accepting this. Type and extent of genital operation, if present, were registered, as well as information on other health conditions. The diagnosis made in

the emergency ward was examined to elucidate whether or not it might have had any relation to the presence of FGM.

### *Socio-economic level*

Socio-economic level was defined by combining criteria as follows:

- *Low level.* Household income less than 30,000 Sudanese Dinars (SD), approximately 115 USD, per month. Does not have house. Low education. Unskilled work.
- *Moderate level.* Household income between 30,000 SD and 150,000 SD (115–575 USD) per month. May rent house. Usually skilled labour, teachers or employees.
- *High level.* Household income more than 150,000 SD (575 USD) per month. Has own house with water and electricity supply. Husband most often has university degree or is businessman.

### *Diagnosis of UTI*

Urine culture indicating a significant amount of bacteria is the golden standard for diagnosing UTI. This was not possible to arrange in the present study. Instead we opted for UTI diagnosis based on dipsticks in combination with symptoms, which has shown satisfactory sensitivity and specificity for starting presumptive treatment in children (54, 55). Urine was analysed by dipsticks (Multistix® 5, Bayer Diagnostics Mfg., Ltd. Bridgend, UK) for leucocytes (leucocyte esterase) and nitrite (product of Gram-negative bacteria). Diagnostic criteria for UTI were:

- positive nitrate test independent of symptoms, or
- + for leucocytes (15/μl) in combination with symptoms from the urinary tract, or
- ++ for leucocytes or more (>70/μl) independent of symptoms.

Axillary temperature was measured. In the presence of UTI criteria and fever more than 38.5 °C, the case was diagnosed as febrile UTI, assumed to be pyelonephritis in the absence of other explanations for the fever.

### *Statistical analysis*

Differences between proportions were analysed by Chi-square test, adjusted by Pearson's or Fisher's exact test, depending on the number of observations. Odds ratios (OR) were calculated with 95% confidence intervals (CI).

For continuous variables such as age and years in school we used a non-parametric test (Mann-Whitney) for significance testing of differences.

### **5.3 Paper V**

To investigate the possible relationship between FGM and primary infertility, we performed a hospital-based case-referent study. Cases and referents were recruited from the outpatient clinics in Khartoum Teaching Hospital and Soba Teaching Hospital during the period March 2003 to June 2004.

#### *Patients*

Cases and referents were consecutive patients fulfilling the inclusion criteria and giving their informed consent to take part in the study. The inclusion criteria for cases were:

1. Seeking medical care for primary infertility
2. Age 35 or under
3. Regular sexual intercourse during two years
4. Normal menstrual cycles for the last one year
5. Never been pregnant
6. Never used intra-uterine device or hormonal contraceptives
7. No previous abdominal surgery
8. Normal semen analysis for husband.

Cases fulfilling these criteria underwent diagnostic laparoscopy at Soba Teaching Hospital.

The inclusion criteria for referents were:

1. Nullipara expecting first delivery
2. Achieving current pregnancy in less than two years of regular sexual intercourse.

The practice of FGM might be changing over time in Sudan, with a tendency towards less severe forms and possibly abandonment of the practice by some (26). Thus age could be an independent factor influencing the risk of undergoing FGM or the severity of the operation. In November 2003 we introduced matching of referents to age of cases  $\pm 2$  years, since at that time we had discovered a different age distribution in the two groups.

## Procedure

Data were collected for both cases and referents by:

- Interview-administered questionnaire about personal data (age, education level, profession, tribe, religion, years of marriage, age at FGM operation where applicable and any symptoms subjectively associated with this operation).
- Genital examination, including classification of FGM.
- Laboratory investigations; serologies for *Chlamydia trachomatis* (IgG EIA species-specific method, Ani Labsystems Ltd. Oy, Helsinki, Finland) and *N. gonorrhoeae* (gonococcal antibody test, GAT (95), Statens Seruminstitut, Copenhagen, Denmark), haemoglobin, blood group and urinalysis for *S. haematobium* ova.
- Weight and height.
- Cases underwent diagnostic laparoscopy to inspect internal genital organs. Tubal patency was tested by perturbation using methylene blue through the cervix while inspecting the fallopian tubes.

Socio-economic level was defined according to the same criteria as for paper IV, described on page 26.

## Statistical analysis

Exact conditional logistic regression, stratifying for age group, was used to compare cases and referents. Using an exact method guarantees that the result will not exceed its nominal significance level, and the confidence interval will always equal or exceed its nominal coverage level. Respondents were stratified into seven age groups,  $\leq 22$ , 23–24, 25–26, 27–28, 29–30, 31–32 and  $\geq 33$  years. In the univariate stratified logistic model cases and referents were compared by extent of FGM (form involving labia majora versus other forms of FGM or no FGM), and in the multivariate stratified model by extent of FGM, years in school (treated as a continuous covariate), socio-economic level (low versus medium and high) and seropositivity for at least one of *N. gonorrhoeae* and *Chlamydia trachomatis* versus negative for both. The two models were fitted using LogXact-5<sup>®</sup> for Windows. The univariate model was based on 278 observations and the multivariate model on 210 observations. Exact odds ratios were calculated with 95% confidence intervals.

To compare cases and referents regarding time interval between the FGM operation and time of observation, the Mann-Whitney test was used.

## 6. Results

### 6.1 Social characteristics of respondents in Papers I–III

Data for Papers I–III stem from the same interviews, which means that the social characteristics of respondents are the same in these three papers. In Paper I all respondents are included, in Paper II only the men, and in Paper III only the women.

The age distribution is shown in Table 2. Most of the respondents in the older groups did not know their exact age. They tended to underestimate their age, which is probably reflected in the figures. In the younger groups, the median age of the oldest child was 3 years for the men (with the oldest child being 15) and 4 years for the women (with the oldest child being 13). Two young men and three young women had not yet had children.

**Table 2. Age distribution of the respondents**

	Median age	Range
Young women	26	20–30
Grandmothers	60	45–85
Young men	35	26–43
Grandfathers	65	50–82

There was a large difference between the young and older groups in terms of their level of education. Many grandparents were illiterate, but none of those in the younger groups; hence, comparisons related to education level do not include the older groups. The education levels for the different groups are listed in Table 3.

Almost all grandfathers were farmers, but only one-third of the young men. In the latter group there were many workers and some merchants. All the grandmothers were housewives and had no occupation outside the house, but this was true for only two-thirds of younger women. The rest worked as teachers, health staff or students.

**Table 3. Level of education (highest level attended) in the different groups**

	<u>Young women</u>		<u>Grandmothers</u>		<u>Young men</u>		<u>Grandfathers</u>	
	n	%	n	%	n	%	n	%
Illiterate	–	–	20	67	–	–	5	17
Koran school	–	–	–	–	–	–	17	57
Primary school	2	7	10	33	7	24	4	13
Intermediate	10	33	–	–	4	14	3	10
Secondary	15	50	–	–	12	41	–	–
University	3	10	–	–	6	21	1	3
Total	30	100	30	100	29	100	30	100

## **6.2 The practice of genital mutilation of girls in a rural area (Paper I)**

### *The practice*

All interviewed women had undergone FGM; all were infibulated except one young woman who had undergone clitoridectomy. All grandparents had let their first daughter undergo FGM. Thirty percent of young women and 53% of young men were sure that their daughter should undergo FGM, whereas 50% of young women and 38% of young men had decided not to let their first daughter undergo FGM. At the time of the study, only two of the young men and four of the young women had let their eldest daughter undergo FGM. This had been carried out between 4 and 7 years. The grandparents' daughters underwent FGM at the median age of 7 years, ranging from 2 to 12 years.

There had been a shift from infibulation, preferred by previous generations, to clitoridectomy, which was the form predominantly preferred by the younger generation ( $p < 0.001$ ) (Table 4). Out of the young respondents who had already let their daughters undergo FGM, four chose clitoridectomy, one intermediate and one infibulation.

### *Determinants of the practice*

The level of education played an important role in the young women's decisions. Significantly more of those with higher education (secondary school and university) did not want to let their daughters undergo FGM ( $p < 0.03$ ). There was no such difference related to level of education among young men.

More men than women thought that there was religious support for FGM (56 and 33%, respectively,  $p < 0.03$ ). Only 27% of the younger women found support for FGM in Islam, compared with 55% of young men. There is no significant difference between the young and older groups in this regard. Most of those who believed in support for FGM in Islam related it to clitoridectomy, the form they called sunna. Twenty-two percent of all believed that FGM is against the teachings of Islam (young women 20%, older women 17%, young men 28%, and older men 23%). Level of education did not affect the degree to which young people believed in support for FGM in Islam.

Religious interpretation of FGM was of vital importance when considering whether their daughter should undergo FGM or not. Significantly more of those who believed in religious support for FGM would let their daughter undergo the procedure than of those who did not believe in this support ( $p < 0.01$ ).



**Table 4. Preferred form of FGM by those who have let or will let their daughter undergo the procedure**

	<u>Young women</u>		<u>Grandmothers</u>		<u>Young men</u>		<u>Grandfathers</u>	
	n	%	n	%	n	%	n	%
Clitoridectomy	14	93	1	3	16	89	4	13
Intermediate	1	7	3	10	–	–	1	3
Infibulation	–	–	25	83	1	5.5	19	63
Unable to specify	–	–	1	3	1	5.5	6	20
Total	15	100	30	100	18	100	30	100

**Table 5. The individuals behind the decision to perform FGM**

	Young women	Grandmothers	Young men	Grandfathers
	n=9	n=30	n=18	n=30
Mother	6	21	7	20
Father	–	1	4	2
Both parents	3	8	3	1
Other answers	–	–	4	7

The decision makers in cases of FGM are listed in Table 5. While the girl's mother was said to be the decision maker in most cases of FGM, the girl's father was more involved when there was a decision not to perform FGM. Out of the 11 young men who did not intend to let their daughter undergo FGM, eight said that they themselves were behind that decision. The other three said that both parents had made the decision. Of the 15 young women who intended not to let their daughters undergo FGM, eight said that this was a decision taken by both parents together, six answered that they themselves were behind that decision and one said that the child's father had refused.

The answers to the question about motives for performing FGM are listed in Table 6. Note that this was a general question about others' motives answered by all subjects, i.e. even those who did not agree with the practice, whereas in Table 7 the personal motives for letting their own daughter undergo FGM are listed. The motive for those who did not want their daughter to undergo FGM, was simply that they wanted her to avoid the suffering that FGM causes, sometimes specified as avoiding problems of delivery.

**Table 6. Answers to the question: why do you think people perform female circumcision? <sup>a</sup>**

	Young women n=30	Grandmothers n=30	Young men n=29	Grandfathers n=30
Tradition	11	23	18	20
Ensure virginity/decrease sexual desire	7	3	19	6
For the future husband/satisfy husband/men prefer it	16	9	2	2
Socially important	7	6	1	3
Women tradition/grandmothers push	4	2	2	1
Increase fertility/good for health/cleanness	4	4	–	2
Religious reason	–	–	4	7
Other reason	2	3	–	1

<sup>a</sup> Answered by all subjects. Some individuals gave more than one answer.

**Table 7. Motives mentioned for letting own daughter undergo FGM <sup>a</sup>**

	Young women n=9	Grandmothers n=30	Young men n=18	Grandfather n=30
Tradition	1	12	5	21
Socially important	11	10	7	8
For the future husband	3	6	2	3
Less severe form to avoid sufferings of pharaonic	2	1	5	1
Women tradition/grandmothers push	2	1	3	–
Ensure virginity/decrease sexual desire	1	–	2	1
Religious reason	–	–	2	2
Other reason (health, fashion, beauty)	1	1	–	2

<sup>a</sup> Some individuals gave more than one answer.

### 6.3 Male complications and attitudes (Paper II)

#### *Female and male complications of FGM*

Most respondents (90% of the young men and 70% of the grandfathers) believed that FGM affects women's health. Level of education seemed to play an important role. Among the young men, the few who denied health effects of FGM (n=3) had only been to primary school. All those answering that FGM influences health gave examples of female complications (Table 8). Nobody mentioned positive health effects.

When asked whether men face any problems because of FGM, 63% of all respondents (72% of the young men and 53% of the grandfathers) replied in the affirmative. Those admitting problems were then asked to specify what kind of problems men face because of FGM. The answers to this open question are listed in Table 9.

#### *Attitudes towards women who have not undergone FGM*

In answer to the question of what people in the village would think about a Sudanese woman who had not undergone FGM, most of the interviewed men thought that it would be socially very difficult for her. On the other hand, 24% thought that it would be no problem at all (Table 10).

**Table 8. Alleged health consequences of FGM expressed by young and old men**

Health effects of FGM	Young men (n=26)	Grandfathers (n=21)
Difficult deliveries	20	11
Infections/inflammations/diseases	11	5
Difficulties/suffering from sexual intercourse/decreased libido	9	4
Menstrual problems	4	2
Bleeding and suffering during the operation	6	7
Might cause death	3	4
Infertility	2	–
Abortions	2	1
Psychological problems	1	2
Difficult pregnancies	1	1
Changes God's creation	–	1
Can't keep clean	–	1
Unspecified	2	4

**Table 9. Male problems from FGM expressed by young and old male villagers**

Male problems from FGM	Young men (n=21)	Grandfathers (n=16)
Difficulties to penetrate	18	16
Wounds/bleeding/inflammation on penis	6	4
Psychological problems	3	1
He hurts his wife/she suffers	3	3
Decreased sexual desire and enjoyment for the woman	3	–
Economic problems (costs for medical care)	2	–
Problems after reinfibulation	2	–

**Table 10. Attitudes the individuals interviewed thought people would have towards a village woman without FGM**

	Young men (n=29)	Grandfathers (n=30)
Shame/socially unacceptable/people turn away/insult her	17	19
No problem nowadays/people wouldn't care/know	7	7
Nobody would marry her/reason for divorce	4	6
Blame parents for not caring enough for their daughter	–	4
Depends on level of knowledge/education/age	4	1
Lost part of her religion	–	2
Not correct way according to tradition	1	–
Not a complete woman	–	1
Doesn't exist/couldn't imagine	–	1

All men were married to women who had undergone infibulation, except one young man whose wife had had a clitoridectomy. Eighty-six percent of young men would have accepted a woman without FGM to be his son's or grandson's wife compared to 57% of old men ( $p<0.03$ ).

When asked if they would have preferred to marry a woman who had undergone FGM or a woman who had not, 55% of the young men said they would have preferred to marry a woman who had not undergone FGM, compared to 13% of the grandfathers ( $p<0.01$ ), while 35% of the young men and 80% of the grandfathers preferred to marry a woman who had undergone FGM. The rest did not know or did not care. There was no difference related to level of education in the young group. Reasons mentioned for preferring a woman who had or had not undergone FGM are listed in Table 11 and Table 12, respectively. Of the men who preferred to have a wife who had undergone FGM, two-thirds would want the FGM to have been a clitoridectomy and only one-third wished for infibulation.

**Table 11. Reasons for preferring to marry woman who has undergone FGM**

	Young men (n=10)	Grandfathers (n=24)
To be socially accepted	2	9
Tradition	4	4
Religious	2	5
Non-circumcised has too much sexual desire	2	1
No choice	–	3
Good for him	–	3
To be sure that she is a virgin	1	1
Good for her	–	1
Good for both	–	1
Clitoridectomy to avoid complications of infibulation	1	–
No knowledge about different forms	1	–
Unspecified	–	1

**Table 12. Reasons for preferring to marry a woman who has not undergone FGM**

	Young men (n=16)	Grandfathers (n=4)
Avoid problems of delivery	11	1
More sexual enjoyment/avoid suffering during sex	7	1
Because of the suffering a circumcised woman has to face	3	2
Wants her to be as she was created	1	–
Avoid costs for medical care	1	–
Unspecified	1	1

## 6.4 Reinfibulation (Paper III)

### *Practice*

All women interviewed had undergone FGM. All were infibulated except one young woman who had undergone clitoridectomy. There was no significant difference between the generations concerning the practice of reinfibulation. All grandmothers were deinfibulated for delivery and all except one had been reinfibulated. Out of the 27 young women who had children, 4 had had caesarean sections and 23 had delivered vaginally. In the latter group all had been deinfibulated; 20 had been reinfibulated and three had not. All the questions concerned the first delivery. Six of the young women said that they did not want to be reinfibulated after the next delivery, due to the complications they had faced.

### *Postcaesarean intervention*

None of the four women who had had caesarean section had been reinfibulated, but two of them said that they had been expected to have it performed. A 22-year-old woman, with one child, who had delivered by caesarean section, said,

*I decided not to do it. My relatives and the midwife said I should do it. They asked me and my friend, who also recently had a caesarean section, many times if we should not get tighter. At the hospital I heard how other women who had undergone caesarean sections asked the midwife to come to their homes to perform the tightening. I was strong in my decision thanks to my husband who said that I had to stand against my grandmother's and the midwife's demands.*

Another woman, 21 years old, who also had delivered her only child by caesarean section, said,

*I refused to be reinfibulated after the caesarean section, though my mother wanted it. My husband supported me in my decision. He did not want me to go through such suffering again. I am very happy for this now. We are often told by older women that men want the tightening, but I have not heard it from men.*

### *The reinfibulation decision*

The categories of individuals alleged, by the women themselves, to have been primarily responsible for the decision to perform reinfibulation are listed in Table 13. Two of the three women who were not reinfibulated after vaginal delivery said that they themselves

**Table 13. The categories of individuals behind the decision to perform reinfibulation. Answered by the women who had been subjected to reinfibulation**

	Young women (n=20)	Grandmothers (n=29)
Midwife	11	4
The woman herself	4	15
Her mother/female relatives	5	8
No answer	—	2

had made that decision. The remaining woman said it was a decision made by her and her husband together.

The following examples from the interviews demonstrate different decision patterns.

A young woman, 27, three children:

*I did not want to be reinfibulated, but I let it be done. The midwife said it was her responsibility to do it, because otherwise my husband would get angry. She said it is very important for the satisfaction of the man.*

A grandmother, over 60, with eight children:

*The nurse decided to extend the sewing without asking me. I did not want it.*

A young woman, 30, with one child alive and one dead:

*I refused to be reinfibulated, because of the suffering I had experienced. I had severe menstrual and abdominal pain before marriage and then pain during sexual intercourse.*

A young woman, 28, with two children:

*I did not want to be reinfibulated after my second delivery. My husband supported me because of the complications I had after my first reinfibulation, for instance with sex.*

### *Motives*

The admitted motives for performing reinfibulation are listed in Table 14. The motives for the few who did not perform reinfibulation were mainly to avoid complications, such as pain, infections, and difficult deliveries, but one also mentioned religious reasons for not doing it. The following answers are examples of different motives.

**Table 14. Motives for reinfibulation after delivery**

	Young women n=20	Grandmothers n=29
For the husband (to satisfy the husband)	14	10
Tradition/normal thing to do/social reason	2	8
Satisfaction for both husband and wife	–	2
Needed (to make incision heal/avoid infection)	–	1
The parturient's mother (female relatives) insisted	1	–
Unspecified/do not know	1	1
Unwilling to answer	2	7

A grandmother, over 45, with nine children, told us that the main motive for her reinfibulation was the satisfaction of her husband. She also said:

*It is important not to be a disgrace to society. If you are not a decent woman, you and your mother will be insulted. It is not good for a woman to deliver herself, without assistance. It will be too fast if she is not sewn properly. If a woman is not properly sewn she will be insulted to be as the Falatia [Nigerian women in the camps, author's remark], who have their babies in the field or anywhere. The Arabic women are more proud than other women, because they need a lot of help and attention at the delivery.*

A woman, about 30, with four children alive and two dead:

*After my first delivery the midwife made me more tight, to be as before marriage, without me knowing or allowing it. But, after my following deliveries I wanted it, because of my husband's satisfaction and because I do not want people to talk about me.*

### *Complications*

The interviews revealed that reinfibulation might be associated with several serious complications, such as bleeding, obstructed labour, abscess formation, chronic pain, and sexual problems. Several respondents also mentioned death to be associated with the practice.

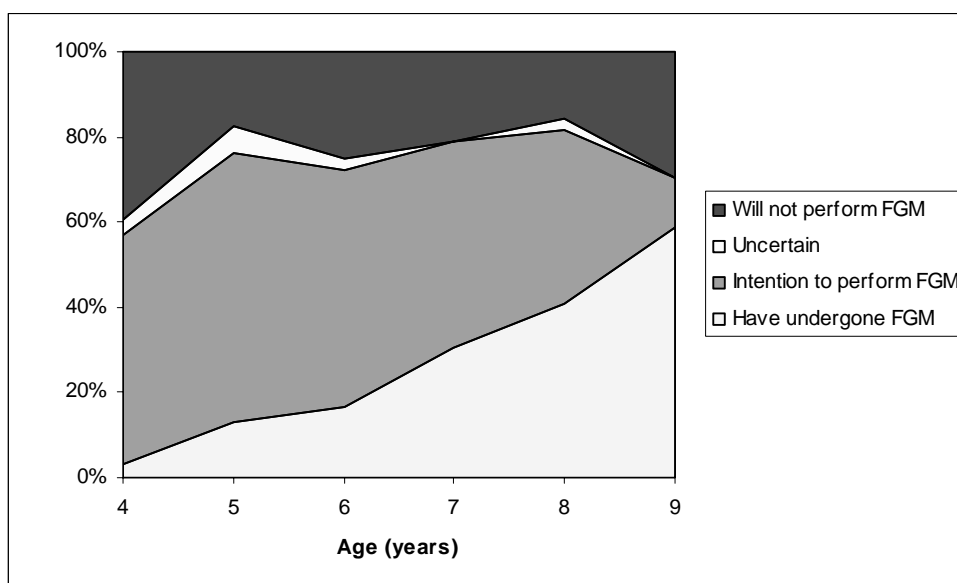


## 6.5 Urogenital complications of genital mutilation in girls (Paper IV)

### *The study population*

Out of 255 girls entering the study, the guardians of 249 girls accepted full examination including inspection of genitalia. The median age was 6 years (range 4–9). The most common complaints were fever (62%) followed by cough (47%), vomiting/diarrhoea (22%) and abdominal pain (19%). Twelve girls (4.7%) had complaints from the urogenital area, mainly burning micturition. No girl presented with immediate effects of recently performed FGM operation.

Fifty-two girls (20%) had undergone FGM. For a large share of the rest, there was an intention to do it, leaving 61 (24%) allegedly without FGM in the future (Figure 3). Out of the 48 girls with FGM, on whom it was possible to inspect genitalia to verify the form of FGM, 13 (27%) had WHO type I, three (6.3%) had WHO type II and 32 (66.7%) had WHO type III.



**Figure 3. FGM prevalence in different age groups**

### *Immediate complications of FGM*

Altogether 38 girls with FGM (73%) were reported to have been bedridden for one week or more following the FGM operation. In spite of this, only five of the 52 girls with FGM (10%) were said to have had immediate complications. One had urine retention and fever, and the others had shock with unconsciousness, fever, wound infection and urine retention. All these five FGM operations were performed by midwives. The differences between those with FGM and those without FGM regarding previous history of symptoms from the genitalia (44% and 40% respectively) or previously having sought medical care for genital problems (21% and 13% respectively) were not significant.

### *Urinary tract infection*

According to the diagnostic criteria, 20 out of 51 girls with FGM (43%) and 61 out of 203 without FGM (30%) were diagnosed as having UTI (difference not significant). Only three had positive nitrite; the rest of the diagnoses relied on significant amounts of leucocytes and symptoms. Among girls below 7 years of age, however, those with FGM have a significantly higher risk of UTI than those without FGM, 20% of UTI cases having FGM against only 4.5% of the others (OR=5.2; 95% CI 1.4, 20.7). UTI was not over-represented among those who had undergone FGM during the last year, as compared to those who had it done earlier. Girls who were found by inspection to have a form of FGM that narrowed the vulva had significantly more UTI, according to the criteria, than others, 57% and 30% respectively (OR=3.0; 95% CI 1.2, 8.0). There were only five febrile UTI/pyelonephritis, two out of 52 of girls with FGM, and three out of 203 without FGM.

Most girls with UTI did not have current complaints from the urogenital tract. Only 8% of those diagnosed as having UTI answered positively when asked about urinary tract symptoms. In comparison, 3% of girls with other diagnoses reported such symptoms.

The possibility that UTI criteria have low specificity for UTI, leading to some false positive UTI diagnoses, made us test leucocytes in urine as an independent factor, disregarding the underlying cause. Among girls with FGM, 25% had significant leucocyturia (more than or equal to ++, 70/ $\mu$ l) as compared to 21% among those without FGM (n.s.). Neither form of FGM, age at operation nor vulva narrowing showed any association with leucocyturia. Girls under 7 years of age with FGM tended to have leucocyturia more frequently (29%) than those without FGM (13%), but the difference is not significant ( $p=0.09$  by Fisher's exact test).

### *Social characteristics in relation to the practice*

All 16 Christians in the sample come from ethnic groups traditionally not practising FGM. None of these girls had undergone FGM. For two of them it was said that there was an intention to have it done, but they could not specify what form of FGM. Calculations and comparisons below relating the practice of FGM to social aspects include only the 239 Muslim respondents.

Table 15 shows socio-economic status, parental age and parental education levels for girls who had or were planned to have FGM and for girls who were not supposed to undergo the operation. Those who have or will let their daughter undergo FGM have significantly lower socio-economic status and significantly fewer years in school, for both the mother and father, than those who have/will not. There is no association between parental age and the practice of FGM. Paradoxically, among girls who were over 7, those who had undergone FGM were more likely to attend school regularly. Only one of 28 girls with FGM in this age group, but 10 out of 37 without FGM, did not attend school ( $p=0.02$ , same result when excluding Christian girls). Turning the figures the other way around, among girls over 7 attending school, half had FGM, but among those not attending school only 1 out of 10 had FGM.

**Table 15. Social characteristics of Muslim respondents <sup>a</sup> in Paper IV**

	Socio-economic level <sup>b</sup>			Mother's age		Mother's years in school		Father's age		Father's years in school	
	Low	Medium	High	Median	Range	Median	Range	Median	Range	Median	Range
Have or will have FGM (n=171)	152* 89%	18 11%	–	29	18–45	3**	0–13	39	25–70	5***	0–17
Will not have FGM (n=61)	42 70%	17 28%	1 2%	30	19–45	6	0–16	40.5	27–60	7	0–17

\* OR=3.62; 95% CI 1.6, 8.1

\*\*  $p=0.0015$

\*\*\*  $p=0.0266$

<sup>a</sup> Leaving out those uncertain whether the girl should undergo FGM or not (n=7).

<sup>b</sup> Missing data for two girls makes the sum not add up to total for socio-economic level.

### *The FGM operation*

The median age for the FGM operation was 5 years (range 1–9). With the inclusion of all girls where there is an intention to perform FGM, the overall median age for the operation is 7 years (range 1–12).

Most FGM operations had been performed by trained midwives (63%), followed by traditional birth attendants, TBAs (33%). One clitoridectomy had been performed by a doctor. TBAs tend to be more prone to stitch the sides together, 88% having done WHO type III, compared to 58% of the midwives ( $p=0.085$ ).

The different forms of FGM among Muslim girls are described in Table 16. This table cross-tabulates the reported form of FGM to the WHO classification as noted by inspection of the genitalia. Data from those who did not allow inspection of genitalia ( $n=6$ ) or did not report form of FGM ( $n=1$ ) are not shown in the table. The term “Sunna” is believed to describe forms affecting the prepuce and/or parts or the whole of clitoris. From clinical inspection, however, it is clear that the clitoris is always damaged in “Sunna”, and 43% of those who were reported to have “Sunna” actually had FGM extending beyond the clitoris, most of them with the labia majora involved.

**Table 16. The reported form of FGM among Muslim respondents and its equivalent in the WHO classification, as described by the doctor by genital inspection.**

Figures in bold in shaded areas represent the expected corresponding form.

<u>WHO classification</u>	<u>reported form</u>				Total
	“no circumcision”	“Sunna”	“Intermediate”	“Pharaonic”	
No FGM	<b>185</b>				185
I		<b>13</b>			13
II		1	<b>1</b>	1	3
III		9 <sup>a</sup>	4	<b>18<sup>b</sup></b>	31
Grand Total	185	23	5	19	232

<sup>a</sup> 5 of these 9 WHO type III did not involve labia majora, but had labia minora cut and stitched

<sup>b</sup> 7 of these 18 WHO type III did not involve labia majora, but had labia minora cut and stitched

## 6.6 Primary infertility as a consequence of genital mutilation in girlhood (Paper V)

### *Study population*

Ninety-nine cases underwent laparoscopy, of which 48 showed adnexal pathology indicating previous inflammation, one laparoscopy was inconclusive (large fibroid made inspection impossible), and the rest were normal. Thirty of the 48 abnormal laparoscopies showed bilateral tubal blockage, the rest unilateral block or adhesions. Altogether, 180 referents were recruited, 91 before matching and 89 after.

All cases and referents were married. Table 17 shows the distribution of age, socio-economic status and education (years in school). For referents data are divided into two separate groups, before and after matching.

There were only six Christians: three cases – one bilateral tubal block (no FGM), one inconclusive laparoscopy (no FGM), and one normal laparoscopy (FGM involving labia majora) – and three referents (two without FGM and one with FGM involving labia majora). The remaining cases and referents were Muslims.

**Table 17. Social characteristics of cases and referents**

	Age			Socio-economy <sup>a</sup>			Years in school		
	Mean	Median	Range	Low	Medium	High	Mean	Median	Range
<b>ALL CASES</b>	<b>27.2</b>	<b>28</b>	<b>18–35</b>	<b>60</b>	<b>35</b>	<b>1</b>	<b>9.9</b>	<b>12</b>	<b>0–18</b>
<b>(n=99)<sup>b</sup></b>				<b>61%</b>	<b>35%</b>	<b>1%</b>			
Cases with tubal pathology (n=48)	28.3	29	21–35	31	15	1	9.9	12	0–18
				65%	31%	2%			
Cases with normal laparoscopy (n=50)	26.0	26.5	18–32	28	20	0	10.0	12	0–18
				56%	40%	0%			
<b>ALL REFERENTS</b>	<b>24.7</b>	<b>25</b>	<b>17–35</b>	<b>94</b>	<b>79</b>	<b>5</b>	<b>11.3</b>	<b>12</b>	<b>0–19</b>
<b>(n=180)</b>				<b>52%</b>	<b>44%</b>	<b>3%</b>			
Referents before matching (n=91)	24.0	24	17–35	53	34	4	11.0	12	0–18
				58%	37%	8%			
Referents after matching (n=89)	25.5	25	18–35	41	45	1	11.6	12	0–19
				46%	50%	1%			

<sup>a</sup> Information on socio-economy missing for some respondents, which means that percentages do not sum up to 100.

<sup>b</sup> One case with inconclusive laparoscopy.

## Form of FGM

The anatomical extent of the FGM operations is described in Table 18, whereas in Table 19 they are classified according to the WHO criteria. The major difference between these classifications is that all types of suturing of the two sides, whether of labia minora or majora, are classified as type III according to WHO. This means that Table 18 shows the effect of the anatomical extent of FGM and Table 19 the effect of FGM suturing. The clitoris was damaged in all cases and referents with any form of FGM. In all forms involving labia minora the clitoris was also cut, and in all forms involving the labia majora, labia minora and clitoris were partially or totally removed. No woman had any sign of being deinfibulated (the bridging scar of type III having been cut).

The median age for the FGM operation was seven years for both cases and referents. Cases with tubal pathology had a longer interval between the FGM operation and our observation, i.e. longer exposure to the possible effects of FGM, median 21.5 years, than cases with normal laparoscopic findings, median 19 years ( $p=0.015$ ).

**Table 18. Anatomical extent of FGM among respondents.**

The columns describe the maximal extent of the operation. For example, a patient classified “labia minora” has undergone FGM involving clitoris and labia minora, but not extending to labia majora.

		no FGM		clitoris		labia minora		labia majora		Total
		n	%	n	%	n	%	n	%	
Infertile cases	Adnexal pathology	1	2.1	1	2.1	–	0	46	95.8	48
	Normal laparoscopy	1 <sup>a</sup>	2.0	4	7.8	–	0	46	90.2	51
Referents		5	2.8	14	7.8	29	16.2	131	73.2	179 <sup>b</sup>
Total		7	2.5	19	6.8	29	10.4	223	80.2	278

<sup>a</sup> One case with inconclusive laparoscopy.

<sup>b</sup> Anatomical classification for one referent missing.

**Table 19. Types of FGM classified according to the WHO classification.**

All forms involving stitching/suturing the two sides together are classified as type III, irrespective of whether labia minora or majora are stitched.

	no FGM		WHO I		WHO II		WHO III		Total
	n	%	n	%	n	%	n	%	
Infertile case	2	2.0	5	5.1	1 <sup>a</sup>	1.0	91	91.9	99
Referent	5	2.8	14	7.8	8	4.5	152	84.9	179
Total	7	2.5	19	6.8	9	3.2	243	87.4	278

<sup>a</sup> A case where labia minora as well as majora were cut, but there was no stitching together.

### *Symptoms*

Immediate complications were reported by very few, and there was no difference between cases and referents. Three cases and seven referents reported having had fever after the operation and two cases and six referents admitted that they had to seek medical care because of immediate complications.

Repeated subjective symptoms of urinary tract infection (more than three episodes) were significantly more common among all cases (39%), and in the subgroup of cases with normal laparoscopy findings (46%), than among referents (26%), OR=1.84 (95% CI 1.06, 3.21) and OR=2.41 (95% CI 1.19, 4.83) respectively. There was no such association for the subgroup of tubal factor infertility if compared with referents. None of the specific forms of FGM was related to repeated urinary tract infection.

### *Factors related to infertility*

Only two women had body mass index (BMI) below 19 (both had tubal factor infertility) and nine cases had BMI over 30 (five of whom had tubal damage).

None of the cases or the referents had ova of *S. haematobium* in the urine.

Out of patients with available serology results, two of 79 cases (2.5%) and three of 137 referents (2.2%) were positive for *N. gonorrhoeae* (n.s.) and 11 of 81 cases (14%) and five of 139 referents (3.6%) were positive for *Chlamydia trachomatis*, OR=4.2 (95% CI 1.3, 16).

Cases with primary infertility had a significantly higher risk of having undergone the most extensive form of FGM involving labia majora than referents, in both the univariate and the multivariate model (Table 20). The two subgroups of cases (adnexal pathology and normal laparoscopy) both show borderline significant associations. Due to missing data (mainly missing sera) 68 observations are missing from the multivariate analysis, which makes the analysis lose power, which in turn affects the results, especially in the subgroups. Suturing the two cut sides together – irrespective of whether the labia majora or minora were sutured (WHO III) – was not significantly associated with primary infertility, in spite of the higher prevalence among infertile.

There were too few cases (n=2) and referents (n=5) without FGM to allow any analysis of them versus those with FGM.

**Table 20. The association between extent of FGM and primary infertility.**

Exact conditional logistic regression (univariate and multivariate) with age group as stratification variable, used in all analyses.

		Univariate model (extent of FGM)		Multivariate model adjusting for extent of FGM, socio-economic level, years in school, <i>N. gonorrhoeae</i> and <i>Chlamydia trachomatis</i> .	
<b>Anatomical classification of FGM (form involving labia majora vs. milder forms or no FGM)</b>	Variable	Odds ratio	95% confidence interval	Odds ratio	95% confidence interval
All cases vs all referents.	FGM	3.62	1.46, 10.3	4.69	1.49, 19.7
Univariate: (n = 99 vs 179)	Socio-ec. level			1.69	0.82, 3.54
Multivariate: (n = 75 vs 135)	Years in school			0.96	0.88, 1.05
	Seropositivity			2.33	0.69, 8.25
Cases with adnexal pathology vs all referents.	FGM	5.74	1.28, 53.5	6.88	0.98, 301
Univariate: (n = 48 vs 179)	Socio-ec. level			1.99	0.74, 5.70
Multivariate: (n = 35 vs 135)	Years in school			0.98	0.87, 1.10
	Seropositivity			2.94	0.60, 15.2
Cases with normal laparo- scopy findings vs all referents.	FGM	3.38	1.10, 13.9	3.66	0.98, 20.7
Univariate: (n = 50 vs 179)	Socio-ec. level			1.58	0.67, 3.84
Multivariate: (n = 40 vs 135)	Years in school			0.93	0.84, 1.04
	Seropositivity			2.06	0.41, 9.66
<b>WHO classification of FGM (type III vs. milder forms or no FGM)</b>					
All cases vs all referents.	FGM	1.71	0.66, 4.86	1.77	0.52, 7.10
Univariate: (n = 99 vs 179)	Socio-ec. level			1.84	0.90, 3.83
Multivariate: (n = 75 vs 135)	Years in school			0.96	0.88, 1.05
	Seropositivity			2.43	0.72, 8.51
Cases with adnexal pathology vs all referents.	FGM	2.23	0.54, 13.6	1.73	0.31, 18.5
Univariate: (n = 48 vs 179)	Socio-ec. level			2.36	0.88, 6.73
Multivariate: (n = 35 vs 135)	Years in school			0.98	0.87, 1.10
	Seropositivity			3.55	0.73, 18.2
Cases with normal laparo- scopy findings vs all referents.	FGM	1.67	0.52, 7.04	1.64	0.39, 10.3
Univariate: (n = 50 vs 179)	Socio-ec. level			1.65	0.70, 4.00
Multivariate: (n = 40 vs 135)	Years in school			0.93	0.84, 1.04
	Seropositivity			2.02	0.39, 9.58



## 7. Discussion

Research about female genital mutilation has, until now, focused on the adult woman. While research related to obstetrics, gynaecology, anthropology and social sciences has provided knowledge valuable for understanding the practice and its consequences for adult women, it has failed to provide the same for the primary victim; the girl child. In this series of five studies we have tried to shift focus away from the adult woman, to other important actors in the context of FGM:

- Men, who are often said to play a central role, directly or indirectly being the proponents of the practice, and
- Girls, who are subjected to the mutilating operations, but suffer in silence since the adult world, including the health care, fail to recognise their problems.

We have explored some fundamental determinants of the practice, which would be important to consider in campaigns against FGM, and showed that genital mutilation has severe sequelae in the girl, some of which will impact on her future ability to reproduce.

### ***7.1 Representativity of the population sample***

Female genital mutilation is a sensitive subject for both the respondent and the interviewer. Thus, it is not strange that other studies have had problems with respondents unwilling to take part in the interviews or unwilling to answer particular questions (26, 96). In the studies performed in the village (Papers I–III) there was a very high response rate. Only one out of 120 eligible villagers was unwilling to participate in this study. In addition to that, the respondents spoke openly about sensitive issues, such as FGM and sexuality. The open attitude of the respondents might be a result of the way the study was performed. Everybody working with the study lived in the village during that time and took part in everyday village life. In addition they were closely connected to the development project with activities in the area. The fact that we tried to avoid being considered as strangers by living in the village and our connection to the development project may have made the villagers more willing to participate fully in the interviews. This connection might also have influenced the answers in other ways. Since the village had been part of a development project, it is possible that the villagers there were more receptive to ideas about the negative impact of FGM on health and marriage than people in Sudan generally are.

By our living in the village, it was important for us to take precautions to avoid contamination of the results. Thus, the research team stayed in a house belonging to the development project to avoid being associated with certain villagers. The respondents were randomly selected, except for young men, all of those fitting the selection criteria being interviewed. None of the respondents was closely acquainted with the interviewers. The young respondents were about the same age as the interviewers and might have given what

they thought were appropriate answers. To avoid bias, open questions where the respondents had to name – for instance – complications themselves were used to give reasons for their answers.

It may be argued that the sample is not representative, since many young males had left the village. However, this out-migration is not a permanent but rather a dynamic situation where the young men stay for periods in cities to earn money but return to their families in the village in between these periods. This was true also for most men participating in the study: they happened to be at home when the survey was undertaken. Thus, one can presume that the men taking part in the study do not differ very much from those who were away.

The whole of the village population at the time of the study is thought to be representative of a village in this area. The village is, however, not representative of Sudan as a whole. The socio-economic conditions in this area are presumably better than in many other regions in Sudan, and the level of education of the young respondents is higher than average (92). It might not be possible to generalise our results, but the study reveals new remarkable findings that should be explored in other areas and points to an approach that might be applicable and useful in other areas where FGM is prevalent.

The setting chosen for the clinical study on girls (Paper IV) represents the only hospital in Khartoum where children are treated for free. Parental socio-economic status and education level indicate that the girls represent a poor urban population. As such, it is neither representative of Sudan nor of the capital with its social dynamics with middle and upper classes. On the other hand, the poor urban people constitute the bulk of the population in Khartoum.

For Paper V, we are aware that there is no ideal group of referents available to recruit from the same population as the cases. Bearing in mind the need for genital examination, the referent group recruited for this study would, however, appear to be the least biased that is practically and ethically justifiable to achieve. Illiteracy levels for women are high in Sudan (18, 92), but our population had a median of 12 years of schooling. On the other hand there is no difference in this regard, or regarding socio-economic level, between cases and referents. Therefore, we consider the results to be generalisable concerning the influence of FGM, even if the study population is not representative of Sudanese women as a whole.

It may be argued that matching introduced a selection bias, and that referents recruited before matching cannot be grouped together with those recruited after. The effect of matching was, deliberately so, higher age among referents, but apart from this, matching did not have any significant effects. Characteristics of cases and referents differ very little, especially considering the general situation for Sudanese women. By stratifying for age when calculating the odds ratios, the age differences between cases and referents were taken into account and compensated for.

## 7.2 Practice

The prevalence of FGM among girls in our clinical study (Paper IV) corresponds to the figures for girls 4 to 10 years of age in Khartoum in the DHS in 1990 (18) (20% and 23.8% respectively). Among school girls aged 10–14 in Khartoum in 1998 almost 85% had undergone FGM (85). It is difficult to compare with studies on the prevalence of FGM among adult women. Our results indicate a future prevalence of FGM among girls in our sample of 74%, which is lower than the DHS figures from Khartoum (96%) (18). In the village, all in the grandparents' generation performed severe FGM on their daughters, but as many as half of younger women and more than one-third of younger men had the intention not to let their daughter undergo FGM. To our knowledge this high proportion deciding not to perform FGM on their daughter has not previously been reported from Sudan. It is, of course, not known to what extent the intention not to let the daughter undergo genital mutilation will be fulfilled, bearing in mind the intricate pattern of decision making. In any case the figures indicate that a majority of the girls will presumably undergo the operation. Thus, even if the estimates from our studies indicate a true change in practice, it is still very slow. The effects of previous legislation and campaigns against the practice seem disappointingly low. It is not known whether the campaigning *for* FGM on religious grounds (97) in recent years has influenced the practice, especially since it has been answered on both medical and religious grounds (98, 99).

In Sudan there are several studies reporting a change of practice from infibulation to clitoridectomy, at least among young educated people (19, 26, 96, 100, 101). This change from infibulation to clitoridectomy was obvious in the DHS as well. Out of those who had undergone FGM, 83.6% had infibulation, 5.5% intermediate forms and 10.9% clitoridectomy. Among women aged 15–25, however, clitoridectomy was relatively more common (about 20%), and infibulation correspondingly less practised (18). In the village the change from infibulation to clitoridectomy was evident, and in our clinical study about 28% of the girls with FGM had undergone clitoridectomy, which also confirms the trend towards less severe forms. According to many villagers this change began approximately 10 years ago. There seems to be a trend towards less extensive operations also among the most severe forms. Traditionally type III (in Sudan called “pharaonic”) involved tight suturing of the cut edges of labia majora leaving only a very small opening for passage of urine and menstrual blood (18). There were no cases of this tight FGM among the girls in this study, and some of the alleged “pharaonic” operations even left the labia majora untouched, suturing only the remnants of the labia minora. In spite of the trend towards less severe forms, however, it must be remembered that two thirds of the girls still undergo extensive forms of FGM where the cut sides are sutured together (WHO type III).

The findings from Paper I have been referred to in discussions concerning the questioning, or re-evaluation, of FGM that takes place in cultures where the practice traditionally has had a stronghold (102, 103). Even if most girls still undergo genital mutilation, this

example of social change might be important. The process of social change is slow. After the initial steps where a few dare to take a new standpoint, the “early converters” follow. The majority will follow in due course. There are examples of social change in relation to FGM, and how this can be used in integrated programmes against the practice (30, 86). The public meetings we arranged in the village after completing the interviews, where we shared the results with the villagers, are one way an emerging social change could be reinforced. From the discussions during these meetings it was clear that people appreciated having a forum to discuss FGM in, and especially to discuss it from the village point of view.

### ***7.3 The validity of reported form of FGM***

The villagers described “Sunna” as taking away the clitoris, but even so one should be cautious when interpreting this. In the clinical study on girls, it was obvious that the validity of reported form of FGM is low. Other studies comparing reported form of FGM with clinical appearance show similar results. Studies from both Nigeria and Tanzania have shown inconsistency between self-reported and clinically determined form of FGM in more than 20 % of the women (104, 105). It is important to be aware of the low validity when conducting studies based on interviews. If the respondents are not asked to describe what they mean by the different words, the results could hardly be interpreted at all.

It was common to use the term “Sunna” for all different forms of FGM. The vague definition of “Sunna” is also important knowledge for the ongoing debate in Sudan, where the “Sunna” form is promoted on religious grounds (97). The “Sunna” form is, in this context, supposed to involve only the removal of the prepuce of the clitoris (18, 97). It is noteworthy that there is not one single case of this operation among the 52 girls and 271 women found to have FGM. In all cases of alleged “Sunna” the clitoris had been damaged, and in 40% the operation reached the labia majora. This confirms previous experiences from Sudan, that the clitoris is always damaged in alleged “Sunna” (9). The over-reporting of “Sunna” can be a result of an attempt to justify what has been done, by using this religious term.

In the context of changing practice, one should be even more attentive to the meaning of traditional terms used. In a study on Somali immigrants in Sweden the respondents claimed to have stopped “circumcision”. When the interviewers probed more into this, it turned out that the reason for this statement was that they stopped the practice as they were used to it in their home country (infibulation). Instead they practiced “Sunna”, which they defined as removing the forbidden (Haram) part (106). This probably corresponds to clitoridectomy, WHO type I.

## **7.4 Social pressure**

Many were uncertain whether or not to let their daughters undergo FGM, and the social importance was said to be a determining factor in the decision process. Most in this group did not want to, but thought it would be socially impossible not to do it. What they did not know was that there were girls in the village who had not undergone FGM and also had passed the normal age for the procedure and, thus, probably would not have to face it.

Social pressure appears to have a strong influence on the practice of reinfibulation as well. Few young women said it was their own decision. Instead, they considered themselves victims. A majority said that the reinfibulation was decided on by the midwife or by the midwife in cooperation with their mother or female relatives. Many said that the midwife did it without asking them, and some women even said they were surprised at the extent of the reinfibulation that had taken place after their first delivery. The question concerned only their first delivery. Some of the young women, who had delivered one child, expressed a desire not to become reinfibulated after future childbirth. However, they also expressed a deep concern for the social implications of not doing it, since parturient women who are not reinfibulated suffer insults. The pressure from older women is strong. The midwives might have their own interest in performing reinfibulation since they get paid for the procedure. Because of their central role it is essential to involve midwives in campaigns against the practice.

Parental education and socio-economic level are significant determinants for the practice of FGM, but social pressure from outside the family might also have a strong influence. Peer pressure on the parents, and also on the girls, could influence the decision to perform FGM. In Sudan and other settings where FGM is the norm, girls who have not undergone the operation might be under considerable pressure from their female friends (17). To avoid this and associated bullying, girls sometimes ask for the operation to be done even when their parents decided not to do it (106, 107). The finding in the clinical study that girls attending school are more likely to have undergone FGM than those not in school, could be interpreted in this context. Another factor might be the traditional belief that FGM protects the girl from immorality and sexual assault (107, 108), a protection for which a need might be felt when the girl leaves home to go to school.

## **7.5 Religious influence**

It is known that there is no authenticated Islamic support for FGM. On the contrary, because FGM inflicts harm, it should not be performed according to Islamic rules (23). In practice the religious dimension of FGM is very complicated, because of the cultural, social and language aspects. All these aspects are tightly linked together in Sudan and cannot be

considered one by one. The terms traditionally used to describe various forms of FGM in Sudan – circumcision, tahour and sunna – also carry religious meanings. Thus, it is not strange that many relate the practice to Islam. In Paper I we show that those who believe in support for the practice in religion also tend to perform it to a higher degree. The important roles of religious belief and the religious meaning of the terms traditionally used to describe FGM show the importance of involving religious leaders in campaigns against FGM.

In other surveys from Sudan, religion has been found to be one of the main motives for performing FGM (26, 109). In the village, however, tradition and social importance, rather than religion, turn out to be the main motives for performing FGM. In spite of the complex religious context of FGM, less than half of the respondents believed in support for FGM in Islam and many believed FGM to be against the teachings of Islam. Even among the older groups who had all let their daughters undergo FGM, one out of five believed that the practice was against their religion. This indicates that the social and traditional impact of FGM is even stronger than that of religious rules.

During the last years there has been a, partly very heated, debate on the religious aspects of FGM. For the first time in modern times, FGM is promoted in Sudan. Female doctors, gynaecologists, who are religious fundamentalists, and the Islamic University in Omdurman promote FGM by lectures and articles and refer to alleged medical and religious (Muslim) benefits (97). The medical arguments, which are based on hygienic aspects, are obviously false, but when mixed with religious arguments based on ambiguous quotations from religious texts, and presented by a female doctor, the mixture of medical and religious arguments gives the message some authority. Well-educated people might see through the false argumentation (98, 110), but for common people the message might seem trustworthy. Unfortunately the government seem to be divided on this issue. While the Ministry of Foreign Affairs and the Ministry of Health work against FGM, other parts of the government seem to support the Islamic University in its campaigns promoting FGM. The Ministry of Health has produced a strategy and plan of action to abolish FGM, and this includes legislative measures against all forms of the practice (111), and official representatives of Sudan have adopted the Cairo Declaration for the Elimination of FGM (112). A law criminalising all forms of FGM is supposed to be pending, but it remains to see how, and if, it will be enforced.

The argumentation for FGM has been met strongly by both religious and medical arguments. One positive effect of this debate is that it has re-awakened many positive forces against FGM in Sudan, such as the medical community, which takes an active stance against FGM. The religious leaders in Sudan seem to be more hesitant to take active standpoints against the practice. In spite of the fact that FGM is not mentioned in the Quran, and that the Hadith, where prophet Mohamed mentions the practice, has proven not to recommend the practice (23), many religious leaders seem more concerned about the popular support for the practice than the well-being of girls and women. This is sad, because they have a key role to play to improve the situation for girls and women in Sudan.

Sudanese are generally very religious, and tend to follow religious recommendations. If the Muslim leaders in Sudan take an active standpoint against the practice, and promote this standpoint, this will very much facilitate work against FGM.

## **7.6 Education**

The more years the mother and father have studied in school, the less the risk that the daughter will undergo FGM. The negative association between female education and FGM found in both our studies is well known (18, 19, 113-115), but it is worth stressing that the same association exists for men, both in our clinical study and in a previous one from Sudan (85). The roles of men and male attitudes towards FGM have attracted more attention lately, a fact that we will address below. Several authors have written about the decisive role of the level of education for the practice of FGM (17, 96, 116-118). According to WHO (36) illiteracy is one of the determining factors for the continuation of FGM. Illiteracy combined with poverty among women aggravates the problem (21). The women's movement is restricted and they are thus not subjected to influences from others to the same extent as men are. On the other hand, the fact that younger women have higher education and work outside the household probably affects their attitudes. The importance of occupation and the exposure and social interaction this brings has been stressed before by Sudanese researchers (96).

As in many other health aspects concerning children, female education also affects the practice of FGM. Education for women is an important factor influencing the practice, and should play a decisive role in future projects to eradicate FGM.

## **7.7 Sexuality and marriageability**

### *Marriageability*

The potential positive role of men in the work against FGM merits attention, especially because of the widespread belief that men demand to marry a woman with FGM (107, 119). Marriageability is often mentioned as one of the main reasons for performing FGM (32-34, 36). In this study, however, the motives were tradition, social importance and avoiding complications rather than "for the future husband". More women than men answered that people should allow FGM to be done for the future husband. Our findings indicate that there might be a misunderstanding between the sexes concerning the value of performing FGM related to marriageability, since the majority of young men would have preferred to marry a woman without FGM. Thus, an efficient way to counteract FGM might be to simply facilitate communication of already existing attitudes and motives. This would

also counteract the social pressure to perform FGM. In a study from Ethiopia it was concluded that if men openly stated a preference to marry non-circumcised women, FGM would probably cease, since the tradition per se did not carry any value to women (34).

Several studies have mentioned marriageability as one of the main reasons for performing FGM (15, 32, 33, 100). In this study most young men answered that they would have preferred to marry a woman without FGM (some frankly giving “more sexual satisfaction” as a reason for this), in spite of the fact that all of them reported being married to women who had undergone FGM. No man mentioned more sexual satisfaction as a reason for preferring a wife with FGM. The answer “good for him” can possibly be interpreted as “good for his sexual satisfaction,” but only old men answered so. The tight opening created when performing infibulation and reinfibulation after delivery is thought to increase sexual satisfaction for men. However, a majority of those wanting a wife with FGM preferred clitoridectomy to infibulation. The significant difference between the young men and the grandfathers as regards which woman they would have preferred to marry shows that attitudes towards women without FGM have changed dramatically and rapidly.

The authors of a study from Ethiopia (34) conclude that men still seem to prefer marriage to circumcised women. It is important to note that this is the presumed preference, since only women were interviewed. To understand the role of men in FGM, the men have to be addressed directly, preferably by men. Otherwise a vicious circle of false expectations could be perpetuated.

Our finding that there are male complications of female genital mutilation has received international attention. Yount and Balk (41) discuss the male complications and attitudes described in Paper II and possible negative effect on fertility, in the context of what they conclude to be a paradox since traditional motives for performing FGM are contradicted by its effect on male attitudes, quality of marriage, fertility and thus ultimately marital stability.

### *Fertility*

For a complication to be relevant as an argument against FGM it must challenge the perceived positive values of the practice. Women’s concerns about impairment of fertility are substantial in Sudan and in other countries where FGM is traditionally practised. Motherhood is the principal source of support, status and security. FGM is often performed in the belief that it will increase future chances of marriage (107), as it is thought to prove virginity and dignity, but also fertility (107, 119). In many areas there is a symbolic association between FGM and fertility (119). There is also a widespread belief that FGM enhances fertility by making the young girl less masculine (clitoridectomy) (107, 119).



The fact that FGM probably causes infertility, challenges these traditional beliefs, and if used correctly, this fact might be a powerful argument against the practice (41, 120).

### *Sexuality*

There was a high level of awareness, especially in the young group, that FGM influences women's health negatively. It is remarkable that a majority of the grandfathers also answered that FGM affects health negatively. These results differ from other studies performed in Sudan (26, 96). Still, in this study the respondents had to name the complications themselves and could not choose from a list with enumerated complications. The complications mentioned cover almost all those related to FGM in the literature, which indicates a high level of knowledge among the respondents.

Different aspects of sexuality turned out to be a central issue. Sexual problems for women attributable to infibulation have been recognised previously in the literature (28, 101, 121, 122). Often the male dimensions of FGM in general and the sexual aspects in particular are not mentioned. In this study, almost two out of three men -but especially the young men- admitted male sexual complications related to genital mutilation of women. In previous studies sexual aspects have been limited to include almost only male satisfaction (100, 123), or FGM as a means of controlling female sexuality (9, 15, 116). The results of this study indicate that the focus should be on sexual problems for both men and women due to FGM rather than on male satisfaction. The fact that the wife is suffering during sexual intercourse affects sexual satisfaction negatively for the man. Our finding that men experience their wives' suffering as their own problem merits attention, since other authors like El Dareer (124) have argued that men let their wives suffer in order to enjoy sex more themselves. One of our respondents (age 34) said:

*I discovered the first night that my wife had a big cyst. She has undergone several operations and suffered from recurrent infections for many years. Sexual intercourse is problematic. I am afraid she will stop loving me if only I reach climax and I can't satisfy her.*

Our results concerning male sexual problems related to FGM (Paper II) were discussed in relation to pain and psychological trauma in the context of coital frequency in a study from the Central African Republic (125). They investigated determinants of coital frequency for married women, but did not find any association of this with FGM. However, the authors stressed that no conclusions could be drawn about the effect of FGM on women's desire for sexual intercourse, since it was not known to what extent women can control coital frequency, and fertility desire may override the negative effect of FGM on sexual pleasure.

### *Reinfibulation as an example of the role of men and sexuality in FGM*

The tight introitus created by reinfibulation is thought to stimulate sexual satisfaction for the husband (9, 17). Reinfibulation has even been referred to as “men’s circumcision” because of this (17). With the same purpose, to increase sexual satisfaction for the man, reinfibulation is sometimes combined with further tightening of the introitus to its virginal state (9).

In Sudan reinfibulation is by and large considered necessary after deinfibulation (27). This is evident in the present study population in which the young women were reinfibulated to the same extent as their parents’ generation. Few question the practice in Sudan, even among health staff and opponents to other forms of FGM. Also some Western doctors (33) seem to not question the practice.

Reinfibulation is widely practiced, also by the younger generation. Few question the practice, and those who do so find difficulties in overcoming the social pressure. There are indications that reinfibulation might carry the risk of several serious complications. Thus it is important to find out more about the practice, in order to understand and be able to counteract it. Other members of the research team have continued exploring the field of reinfibulation, especially the role of midwives (126). The practice of reinfibulation represents a considerable source of income for midwives, but is not the only motive for performing the operation. They integrate the practice of reinfibulation into a greater whole of doing well for the woman, and think it increases her value by helping her to maintain her marriage. Through the procedure, the husband would be reminded of the time when they were first married. This recreation of virginity would help the woman to maintain her marriage, but also decrease the risk of the husband wanting to marry a second wife. On the other hand, some midwives were aware of men being against reinfibulation, with motives similar to those expressed in Paper II (126).

Postcaesarean interventions were not the focus in the present study. However, there were indications that women who delivered by caesarean section also may undergo a “tightening” operation, similar to reinfibulation, with the alleged aim of satisfying the husband. To our knowledge this practice has not been given attention in the literature. This particular form of reinfibulation without prior deinfibulation, would only have one meaning, to bring the woman back to her pre-marital stage, mimicking virginity.

Consequently, two thirds of the women mentioned “for the husband/to satisfy the husband” as the main motive for performing reinfibulation. However, none of them answered that her husband was behind the decision to reinfibulate. This absence of men in decisions to perform “men’s circumcision” is noteworthy. Men were, however, involved in several cases when a decision was made not to perform reinfibulation. Again, bearing in mind the alleged male complications and marriage preferences, we believe there is a misunderstanding between the sexes because of lack of communication about sexuality and

FGM. Some of the few women who decided not to undergo reinfibulation said this was possible only because of the support of their husbands. Such findings would seem to strengthen the need for further research within the field of sexuality and male attitudes toward reinfibulation and other forms of FGM.

### *Male attitudes*

For the men the main motives for preferring a wife who had not undergone FGM were to facilitate delivery and to be able to enjoy sex more. For those who preferred a wife who had undergone FGM the main motives were social acceptance, followed by tradition. This shows that social pressure is of great importance for the men. The common answer “to be socially accepted” has to do with the importance of being respected and marrying a “decent” woman. The Sudanese expression “Rhalfa” (“child of an uncircumcised woman”) is extremely insulting to use. As in many other African–Arab cultures the purity and chastity (linked to the virginity) of the woman reflect the moral quality of the entire family. This makes our findings that so many young men would have preferred a wife who had not undergone FGM even more interesting. It suggests not only that the attitudes of men have changed, but also that there is a change in attitudes in the whole society. This is supported by the fact that other studies in Sudan have noticed similar changes in attitudes. A large study in Northern Sudan (28) showed that the younger and/or better educated people tended to oppose the practice or favour milder forms, which indicated a change of attitudes among these groups. Other Sudanese studies have shown an emerging questioning of the value of the practice (109), intergenerational differences of opinions about FGM (100) and negative attitudes among fathers against the practice (101).

A change in attitude can be the first step towards a change in practice. One of our respondents (grandfather, age 62) bore evidence of such a change. Of his nine daughters (age 10–40), the three youngest had not undergone any form of FGM. Many young respondents told of young families having the ambition not to let their daughters undergo FGM. It was not easy, however, to withstand the pressure from the grandmothers, and there were several stories of girls taken away by their grandmother to have it done.

### *Decision process*

In spite of the fact that women to a large extent still think that they alone decide about FGM, it can no longer be considered to be only a woman’s matter. Young men see themselves as actively involved in the decision process about FGM to a larger extent than older men do. In previous studies fathers have been described as playing a passive role in the decision about their daughters’ FGM (28, 96). Now, however, it seems as if at least the young men try to become more involved in this. A Sudanese study (96) identified the fathers as the main source of objection against the practice when FGM was not performed.

Our results support this finding by showing that the men were involved in most decisions not to perform FGM or reinfibulation. It is important to consider this and to actively involve men in future campaigns against FGM.

### ***7.8 Sequelae of genital mutilation in the girl child***

It is often neglected in the debate that the FGM tradition carries positive values for those practising it. Alleged complications have been used in campaigns against the practice for many years, with little or no effect (14). For a complication to be relevant as an argument against FGM it must challenge these positive traditional values.

The complications for girls described in the literature derive mainly from data reported by adult women. To our best knowledge there are only a few published studies carried out on girls. Descriptive hospital-based studies from Nigeria find that the commonest presenting complication following genital mutilation in girls relates to micturition (dribbling incontinence, straining and retention of urine and urinary tract infections) (43) and that unintentional labial fusion with sequelae is common (42). Early complications, such as haemorrhage, septicaemia and tetanus were encountered, but not to the degree the authors expected (42). Kabira et al. (127) report on an unpublished study from Kenya indicating that FGM contributes to high rates of school dropout for girls. A study on the Somali Family Health Survey shows excess female child mortality in the age group 5–15 years, which is when FGM is performed (128). Other factors than FGM, such as son preference in nutrition and health seeking behaviour, could contribute to this excess mortality. The authors, however, also found that the more severe forms of FGM (assuming that daughters had the same form of FGM as their mother) had higher child mortality than less severe forms.

In the present study we find no clinical signs of current direct complication of FGM, but there were relatively few girls in the series that had undergone the operation. There were also few immediate complications reported. In clinical paediatric practice in Sudan, it is rare to see complications of FGM (Elsir Hashim, personal communication, 2003). There can be several reasons for this, for instance:

- Reluctance among mothers/family members to seek paediatric/medical care in cases of immediate complications after FGM.
- Non-recognition of the entity of FGM as genital trauma within the field of paediatrics.

The findings that only 8% of girls with UTI reported urogenital symptoms and that only 10% stated immediate complications related to the operation, in spite of the fact that 73% of the girls subjected to FGM had been bedridden for one week or more after the operation, imply that symptoms from this part of the body are under-reported. The under-reporting of symptoms from the urogenital tract clearly shows the importance of asking specific

questions relating to this area, routinely performing urinalysis, irrespective of complaints, and inspecting the genitalia on more liberal grounds. Even though genital inspection should be a part of the routine examination of paediatric patients, such inspection is, according to our observations, rarely done. This reluctance to ask about symptoms from the genital tract and to inspect the genitalia implies a failed diagnosis with inappropriate treatment, which in turn might increase the risk of further complications.

*Short term sequelae for the girl: disruption of normal genital anatomy and environment*

Diagnosis of UTI is based on the presence of a significant amount of bacteria in the urine, and the most appropriate method to diagnose this is by culture. For various logistical and practical reasons it was not possible to organise this in the current setting. Instead we used dipsticks in combination with symptoms to diagnose UTI. There are, admittedly, disadvantages with this strategy. Diagnosing UTI in children by dipsticks positive for leucocyte esterase and/or nitrite has shown high sensitivity and specificity (88% and 96% respectively) in a meta-analysis (54), and 2+ for leucocyte esterase or positive nitrite has been suggested as a strategy for presumptive treatment of UTI in children (55). The high proportion diagnosed as having UTI in the present study implies an over-diagnosis of UTI and that these criteria do not work in the present clinical setting. There might be several reasons for this. Other conditions, such as schistosomiasis, which are endemic in Sudan, might also cause leucocyturia. Genital mutilation might cause environmental disturbances that possibly result in accumulation of leucocytes, and the anatomical changes brought about by the operation possibly prevent the free flow of urine and normal cleaning when the sides are stitched. It is known that vulvo-vaginitis and labial adhesions in girls without FGM might predispose to perineal bacterial colonisation with ensuing UTI (53). This may explain why girls having undergone a form of FGM narrowing the vulva were more likely to be classified as having UTI. The results indicate that there might be an association between FGM and UTI, diagnosed by the stated criteria, for girls under 7. This possible association has to be interpreted bearing in mind the limitations of the methodology. Irrespective of where the leucocytes stem from, urinary bladder, urethra or vulva, their presence indicates a disruption of the normal state with, to some extent, inflammation.

UTI has been shown to be significantly associated with FGM among pregnant women, 22.9% of women with FGM having *E. coli* in urine culture compared to 4.6% among controls (82). In a large unselected sample from Sudan 1962–1966 (n=4024), 28% of women with FGM type III had positive urine cultures, compared to 8% of women with FGM type I or without FGM (3). Observations made in descriptive studies on girls (42, 43) support the hypothesis that FGM is a risk factor for UTI in girls. The anatomical changes due to FGM, leading to micturition problems, difficulties in emptying the bladder due to strictures or painful micturition, provide a plausible theoretical framework for the association. The FGM operation could, however, also alter the local environment in the vulva, leading to increased risk of infections. We demonstrate a highly significant

association between the anatomical extent of FGM and primary infertility in young women. Laparoscopic post-inflammatory adnexal changes were not the only explanation for the strong association, since infertile cases without such adnexal pathology showed similar association. Thus one can hypothesise that the FGM operation leads to other physiological or functional changes in the genitalia. This hidden pathology in the girl child does not present clinically until the young woman is unable to conceive, which poses a challenge to both paediatricians and gynaecologists.

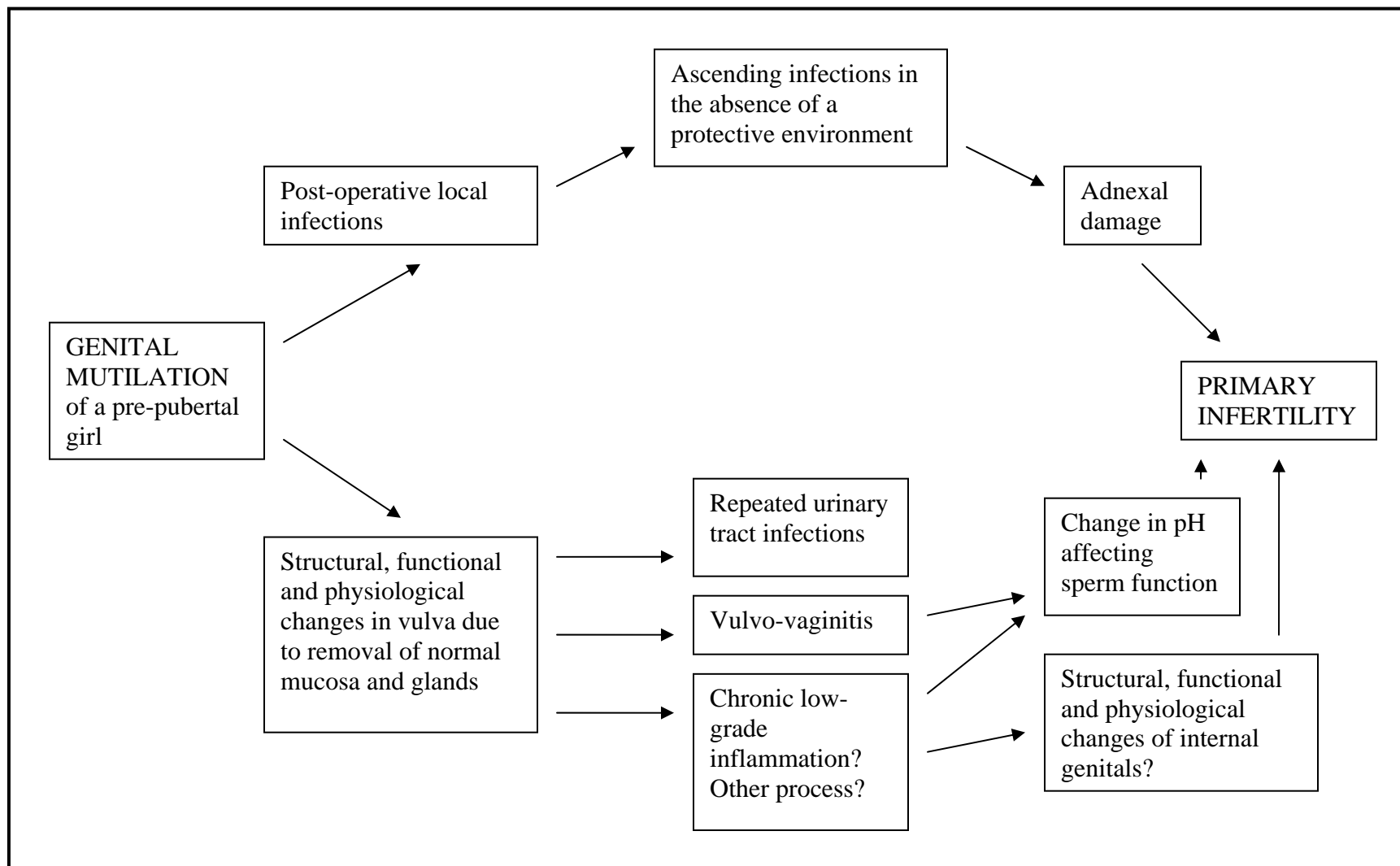
Some unexpected observations concerning the association between FGM and infertility were made. Firstly, it seems that it is the anatomical extent of FGM rather than suturing/closure *per se* (WHO type III) that is associated with primary infertility. Secondly, the group of infertile patients with normal laparoscopic findings shows borderline significance between FGM and primary infertility similar to the group with adnexal pathology. Thus, the macroscopic changes that can be visualised by laparoscopy are not the only factors contributing to infertility. For conception and nidation to take place there need to be normal structure and function all the way from the cervix and endometrium along the fallopian tubes to the fimbriae. FGM might provoke changes in this, for instance by changing the local environment and bacterial colonisation in the vulva/vagina or causing low-grade chronic inflammation. There have been several studies showing an association between FGM and urinary and genital tract infections in adults (80-83). In the present study infertile cases reported more recurrent urinary tract infections than referents, which could indicate disturbances in the local environment.

The age at FGM operation does not differ between fertile and infertile women, but cases with adnexal pathology had had FGM for a significantly longer time than cases with normal laparoscopy findings. This observation gives rise to the hypothesis that the macroscopic findings of tubal pathology could represent a later stage of the same process of FGM-induced inflammatory changes invisibly present in infertile cases with normal laparoscopic findings. Alternatively, the FGM operation also starts another process, parallel to the inflammation leading to adnexal pathology, causing infertility at an earlier stage.

The theoretical basis for the relation of genital mutilation in girls to primary infertility in the adult woman has been described above (page 13), and is outlined in Figure 4.

#### *Sequelae that do not come to clinical attention until the girl has grown up: primary infertility*

This study shows significantly higher risk of severe forms of FGM involving labia majora among women with primary infertility than among fertile referents in Sudan. The odds ratio is high, which indicates that this is not only statistically significant, but also clinically significant and relevant for campaigns against the practice.



**Figure 4. The theoretical framework for how genital mutilation of girls might cause infertility**

With the inclusion criteria male factor infertility, most hormonal causes of infertility and possible iatrogenic PID following surgery were excluded. The distribution of body mass index among cases shows that extremes in weight with associated hormonal changes do not contribute significantly to infertility in our sample.

It might be argued that endometrial curettage should have been done to enable proper diagnosis of genital schistosomiasis and tuberculosis. These diseases often cause irregular bleeding (75, 76), and would thus be excluded from this study. Even though urinary and genital schistosomiasis frequently coincide, urinalysis is not sufficient to exclude genital schistosomiasis (76). It has been estimated that diagnosis based on a single urine examination will miss one third of cases with genital schistosomiasis (129). However, in the absence of clinical findings indicating genital schistosomiasis (schistosoma ova in the urine, significant haematuria, typical symptoms or laparoscopic findings) we conclude that genital schistosomiasis is unlikely to contribute to infertility in the present study. Genital tuberculosis is relatively rare, and often arises secondary to a primary focus elsewhere (75). Genital tuberculosis accounts for less than 2% of all tuberculosis (130), and usually presents with infertility, pelvic pain or menstrual irregularities (75, 130). The fallopian tube is the organ most commonly affected (75). Tuberculosis was not controlled for in this study, but none of cases had clinical or laparoscopic signs of that disease, so its contribution to infertility would probably be small. Only two cases and three referents had serological markers for *N. gonorrhoeae*, which implies that its contribution to primary infertility in Sudan is low. *Chlamydia trachomatis*, on the other hand, seems to contribute to primary infertility in the study population, but the prevalence is low even among cases.

By excluding the known risk factors for primary infertility mentioned above, and showing that the contribution of sexually transmitted infections to the problem is low, we conclude that the association found between FGM and primary infertility is valid. It also indicates that this association is relevant in clinical practice in Khartoum. Since FGM is common in Sudan, it probably contributes more to primary infertility than sexually transmitted diseases do.

Observations from the World Fertility Survey in Sudan 1978/79 show a significant association between the most severe form of FGM and the incidence of infertility five years before the study (131). There have been two attempts to estimate the effects of FGM on fertility in the 1989–90 Demographic and Health Survey (DHS) in Sudan. The first, by Balk (132), does not consider infertile women alone, but includes them in the group of low fertility, defined as having borne two or fewer children. There were no significant effects of FGM on fertility in that study. In the second study based on the DHS, Larsen (133) found that women with infibulation and intermediate forms (both of which in Sudanese colloquial terms correspond to forms involving labia majora) had significantly higher prevalence of primary infertility than women without FGM (OR 2.76).



There have been cross-sectional studies investigating the relation between FGM and infertility, without finding any significant association (83, 105, 115). In these studies, diagnosis of infertility has been made by history only, male factor infertility has not been excluded, and there has not been made any distinction between primary and secondary infertility. Secondary infertility, rather than primary infertility, is the main childlessness problem in Africa (63, 65, 68). Thus, the methods used in these studies will not make it possible to discern the effect of FGM on primary infertility.

To our knowledge there has been only one attempt to perform a clinical case control study on the subject. A study in Egypt 1988–89 compared 100 infertile cases (a mixed group of both primary and secondary infertility) and 90 fertile controls recruited from a hospital in Alexandria (134). The study design has methodological limitations, which have been explored elsewhere (133). There was a tendency for women having undergone excision (type II) to have a higher risk of tubal factor infertility than those having undergone clitoridectomy (type I), but the results were not statistically significant (OR 1.9, 95% CI 0.8, 4.2).

To conclude, there is plausible theoretical support for the hypothesis that FGM can cause primary infertility, and results of epidemiological studies point in that direction. This case-referent study shows strong positive association between the anatomical extent of FGM and primary infertility. The association is not only statistically highly significant, but also highly relevant for preventive work against this ancient practice.

The fact that there is an association between the severe forms of FGM and primary infertility in comparison with milder forms, cannot be used as an argument to medicalise the practice by having doctors perform less extensive forms. On the contrary, it seems likely that any alteration of the normal anatomy of the girl's vulva leads to structural and physiological changes, which in turn have negative effects on her reproductive health.

## 8. Conclusion

Until recently, the social consequences of not letting daughters undergo FGM have been perceived as enormous. This is the first survey of FGM with results both from community-based and clinical studies indicating a significant shift in practice. Young parents seem to start questioning the value of FGM. Even though most girls still undergo severe forms of the mutilating operation, it is evident that there is a change from previous generations. Since the change has started, the rest of the community might now be open for arguments against the practice. Education and economic empowerment for women would also help to lower the support for the practice.

FGM can no longer be considered to be only a matter for women. By exposing male complications resulting from the practice, and attitudes and preferences strikingly different from what might be expected according to the literature, the findings draw attention to the importance of addressing men in future research about and campaigns against FGM. Some may argue that the male complications are only minor ones compared to the suffering women have to face because of FGM. This is true, but the fact that they exist opens possible new ways to work against the practice, especially since marriageability and male satisfaction are often mentioned by women as motives for performing FGM. In this context the practice of reinfibulation exposes some important determinants also for the primary forms of genital mutilation in girls.

Female genital mutilation contributes significantly to morbidity already in childhood. A large share of this does not come to medical attention, partly because symptoms are under-reported and not taken into account by the doctor. Due to lack of scientific studies on how FGM affects girls there is scant knowledge of which signs, symptoms and disease entities relate to genital mutilation. Health care workers need to be aware of this, but also realise that one has to address the problem outside the health care system to fully understand the morbidity impact of FGM, and to be able to help girls who suffer from these effects. FGM has so many socio-cultural interconnections that it cannot be looked upon as a medical problem only.

The results of the research presented in this thesis challenge some of the fundamental motives for performing FGM. By exposing male complications of FGM, showing male negative attitudes towards the practice, male and female sexual problems related to FGM and that FGM is a likely cause of infertility, it challenges the most important marriage-related traditional motives for FGM. Traditionally FGM was performed to increase the chances of future marriage. Our findings, on the contrary, indicate that genital mutilation of girls might have the opposite effect by destabilising marriages through its effect on sexual and reproductive health. This challenges the whole traditional concept of FGM in relation to marriage.

## **8.1 Recommendations for future research**

Several results in this thesis indicate that there might be environmental changes in the girls' vulva following genital mutilation, changes that in turn might be risk factors for infections and infertility. To follow up and clarify this, it would be important to explore the field of paediatric gynaecology in a Sudanese setting. The underlying causes of leucocyturia and vulvovaginitis in Sudanese girls could be investigated, using for instance culture for bacteria (both from vulva and urine) and urine analysis for *S. haematobium* ova.

While several results indicate the existence of severe complications for the girl, it is also clear that the full extent of morbidity impact of FGM on the girl child is not visible within the health care system. Thus it would be important to approach girls outside this, in order to see how FGM affects their daily life. This could concern physical and psychological symptoms for which they do not seek medical care, school attendance and performance, but also attitudes, not least about the role of women and men in the society. This demands an interdisciplinary approach where professionals from different areas cooperate with the girl in focus.

The best way to study how genital mutilation affects girls is to do a prospective study, following a cohort of girls from early childhood till puberty. The inherent difficulties in such a study design require devotion and commitment from those involved, and ability and patience to await results many years from now.

Finally, the most important aspect is how research results are best used. The knowledge gained must be transferred into action. Therefore, researchers and activists must come together, and let the knowledge of the others enrich their own work. Until recently there has not been much research in this area, but there are examples of organisations and networks with this ambition, such as SNCTP (6), INTACT (135) and RAINBO (136), which is promising for the future.

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## 11. Appendix

### Questionnaires used for Paper I-III

## QUESTIONNAIRE FOR WOMEN IN THE VILLAGE

1. married woman below 25 years of age <-> grandmother
  2. age:
  3. number of children: sons:                                ages  
                                 daughters:                                ages
  - number of grandchildren:
  4. tribe:
  5. education: illiterate     primary     intermediate     secondary     university
  6. occupation:
- 
7. How old were you when you married?
  8. What do you think is the minimum age for getting married?
  9. Do you know of any disadvantages of getting married too young?  
-if yes specify
  10. Do you know of any other harmful traditional practices?
  11. If female circumcision is not mentioned: Do you consider female circumcision to be one of the harmful traditional practices?
  12. Do you think female circumcision influences health or diseases in any respect?
- If 12=yes: Q13**
13. In what way?
  14. Why do you think people perform female circumcision?
  15. What does your religion say about female circumcision?
  16. Do you know of different forms of female circumcision?  
If yes: specify
  17. Do you know what different parts are taken in each type?
  18. If there was a woman in the village who was not circumcised. What would people think about her?
  19. Would you accept if your (grand)son wants to marry a non-circumcised woman?

### ***Questionnaires used for Paper I-III***

20. Are you circumcised?

**If Q20=yes then ask Q21-28, If Q20=no then ask Q29-30**

21. At what age?

22. What kind of circumcision was performed on you?

23. Who decided that you should be circumcised?

24. If you had the possibility to choose, would you still have done it?

25. Were you de-circumcised when you delivered your child(ren)?

26. Were you re-circumcised afterwards?

27. Who decided?

28. If you decided; why did you want it? What were the motives for the one who decided?

**If Q20=no then Q29-30**

29. Why not?

30. Who encouraged that decision?

31. Is your first daughter circumcised?

**If no daughter yet; then Q39**

**If Q31= yes Q32-37, If Q31=no then Q38-**

32. Why?

33. At what age?

34. What form of circumcision was performed on her?

35. Who decided that she should be circumcised?

36. Was there a celebration when she was circumcised?

37. Did she get gifts?

**If Q31=no then Q38-**

38. Why?

39. Will she be? /If no daughter yet: If you will get a daughter, will she be circumcised?

**If Q39=yes then Q40-43 if no ask a) why and b) who is behind that decision**

40. Why?

41. At what age?

42. What form of circumcision will be performed on her?

43. Who will take the decision that she should be circumcised?

44. Do you think the number of circumcised girls will increase or decrease the coming 20 years?

45. Why?



### Questionnaires used for Paper I-III

## QUESTIONNAIRE FOR MEN IN THE VILLAGE

1. married man below 35 years of age <-> grandfather
2. age:
3. number of children: sons:                                      ages                                      grandchildren?  
daughters:                                      ages
4. tribe:
5. education: illiterate    primary    intermediate    secondary    university
6. occupation:
7. How old was your wife when you married her?
8. What do you think is the minimum age for a woman to get married?
9. Do you know of any disadvantages of getting married too young?  
-if yes specify:
10. Do you know of any other harmful traditional practices?
11. If female circumcision is not mentioned: Do you consider female circumcision to be one of  
the harmful traditional practices?
12. Do you think female circumcision influences health or diseases in any respect?  
**If 12=yes: Q13**
13. In what way?
14. Why do you think people perform female circumcision?
15. What does your religion say about female circumcision?
16. Do you know of different forms of female circumcision?  
If yes: specify
17. Do you know what different parts are taken in each type?
18. Who in the family decides about female circumcision?
19. If there was a woman in the village who was not circumcised. What would people think about  
her?
20. Would you accept if your (grand)son wants to marry a non-circumcised woman?
21. Before you were married, would you have preferred to marry a circumcised or non-circumcised  
woman?

**Questionnaires used for Paper I-III**

48. Why?

49. If circumcised wife preferred; specify form of circumcision:

50. Is your wife circumcised? what form?

51. Was she de-circumcised when she delivered your child(ren)?

52. Was she re-circumcised afterwards?

53. Why?

54. Who decided?

55. Do men face any problems because of female circumcision?

\_\_\_yes ->specify:

\_\_\_no

31. Is your first daughter circumcised?

**If no daughter yet; then Q39**

**If Q31= yes Q32-37, If Q31=no then Q38-**

32. Why?

33. At what age?

34. What form of circumcision was performed on her?

35. Who decided that she should be circumcised?

36. Was there a celebration when she was circumcised

37. Did she get gifts?

**If Q21=no then Q28-**

38. Why?

39. Will she be? /If no daughter yet: If you will get a daughter, will she be circumcised?

**If Q39=yes then Q40-43 if no ask a) why and b) who is behind that decision**

40. Why?

41. At what age?

42. What form of circumcision will be performed on her?

43. Who will take the decision that she should be circumcised?

44. Do you think the number of circumcised girls will increase or decrease the coming 20 years?

45. Why?

## Data collection form for Paper IV

CASE NUMBER: \_\_\_\_\_

Date: \_\_\_\_\_

Doctor: \_\_\_\_\_

### 1. Personal data

1.1 Age \_\_\_\_\_ 1.2 Tribe \_\_\_\_\_ 1.3 Originally from : \_\_\_\_\_ 1.4 Residence \_\_\_\_\_ since: \_\_\_\_\_

1.5 Religion: ☐ Muslim ☐ Christian ☐ other:

1.6 Attend school regularly? ☐ YES ☐ NO If yes, since age: \_\_\_\_\_

1.7 Mother's age \_\_\_\_\_

1.10 Father's age \_\_\_\_\_

1.8 Mother's years in school \_\_\_\_\_

1.11 Father's years in school \_\_\_\_\_

1.13 Socio-economic level:

1.9 Mother's profession \_\_\_\_\_

1.12 Father's profession \_\_\_\_\_

☐ low ☐ medium ☐ high

1.14 Informant:

☐ mother ☐ father ☐ grandmother ☐ grandfather ☐ aunt ☐ other:

1.15 Complaints (reason to come): \_\_\_\_\_

### 2. Lab

2.1 Temperature: \_\_\_\_\_

2.3 Dipstick:

2.3.1 glucose \_\_\_\_\_

2.4 Admitted: ☐ YES ☐ NO

2.2 CRP: \_\_\_\_\_

2.3.2 leucocyte \_\_\_\_\_

2.5 Treatment:

2.3.3 Nitrite \_\_\_\_\_

2.3.4 Protein \_\_\_\_\_

2.3.5 Blood/Hb \_\_\_\_\_

### 3. History:

3.1 History of UTI ☐ no ☐ 1 ☐ 2-3 ☐ 4-5 ☐ >5

3.2 Previous history of seeking medical treatment/advice regarding genitalia ☐ YES ☐ NO

3.3 History of symptoms from uro-genital tract:

☐ dysurea ☐ itching ☐ discharge ☐ loin pain ☐ recurrent abdominal pain ☐ others:

### 4. Questions about female circumcision

4.1 Circumcised? ☐ YES ☐ NO

4.2 If no: intention to circumcise? ☐ YES ☐ NO ☐ Don't know

4.3 If yes: at what age: \_\_\_\_\_ years

4.4 Form of circumcision: ☐ Sunna ☐ Intermediate ☐ Pharaonic ☐ Other:

4.5 Performed by: ☐ doctor ☐ trained midwife ☐ TBA ☐ Medical assistant ☐ Other:

4.6 How many days bedridden after the operation \_\_\_\_\_

4.7 Immediate complications:

☐ Bleeding ☐ Fever ☐ Wound infection ☐ urine retention ☐ Other (specify): \_\_\_\_\_

4.8 Seek medical care because of complication ☐ YES ☐ NO

4.9 Health care provider: ☐ doctor ☐ trained midwife ☐ TBA ☐ Medical assistant ☐ Other:

### 5. Genital Inspection

5.1 Acceptance: ☐ Accept ☐ Don't accept

#### Findings:

5.2 Clitoris: ☐ untouched ☐ partially removed ☐ totally removed

5.3 Labia minora ☐ untouched ☐ partially removed ☐ totally removed ☐ stitched

5.4 Labia majora ☐ untouched ☐ partially removed ☐ totally removed ☐ stitched

5.5 If stitched, size of opening left: ☐ 1mm ☐ 5mm ☐ 1cm ☐ normal

5.6 Abnormal findings: ☐ inclusion cysts ☐ discharge ☐ infection ☐ other:

### 6. Diagnoses

6.1 \_\_\_\_\_ 6.1.1 Relation to FGM: ☐ YES ☐ NO ☐ possibly

6.2 \_\_\_\_\_ 6.2.1 Relation to FGM: ☐ YES ☐ NO ☐ possibly

**Data collection forms for Paper V****INFERTILE CASES**

CASE NUMBER:\_\_\_

Recruited from centre                      KTH                      Soba

Name

Age

Address

Phone

Religion

Tribe

Socio-economic level:                      low                      medium                      high

Total number of years in school (from primary including university):\_\_\_\_\_

Profession

Married since

Husband's age

Husband's total number of years in school (from primary including university):\_\_\_\_\_

Husband's profession

**Inclusion criteria (please tick)**

Seeking medical care for primary infertility?

Less than or equal to 35 years of age?

Regular sexual intercourse for a minimum of two years?

Normal menstrual cycle for the last one year?

Never been pregnant?

Never previous abdominal surgery (including laparoscopy)?

Never used intra-uterine device?

Not used hormonal contraceptives (tablets or injections) for the last two years?

\_\_\_\_\_

Information on this page filled out by Dr.....date.....

**History**

Circumcised?                      Yes                      No

Age at circumcision?                      \_\_\_\_\_                      If not certain range: \_\_\_\_\_

Reported form of circumcision                      Type 1                      Type 2                      Type 3                      Other

If other form, specify

Fever after the circumcision?                      Yes                      No                      Don't remember

Seek medical care after circumci                      Yes                      No                      Don't remember

Admitted after circumcision?                      Yes                      No                      Don't remember

Cause of seeking care/admission:

History of UTI?                      Yes                      No

Number of UTI episodes?                      0                      1-3                      &gt;3

Age at menarche?                      \_\_\_\_\_

Kata                      ...../.....

Regular?                      Yes                      No

Primary dysmenorrhoea?                      Yes                      No

Secondary dysmenorrhoea?                      Yes                      No

Menorrhagia                      Yes                      No

Metrorrhagia                      Yes                      No

**Examination**

Weight: \_\_\_\_\_kg                      Height: \_\_\_\_\_cm

Observed form of circumcision                      Type 1                      Type 2                      Type 3                      Other

<u>Anatomy:</u>	Untouched	Partially removed	Totally removed	Sides stitched together
Clitoris				
Labiae minora				
Labiae majora				

Other findings (e.g. fenestrations of infibulation, inclusion cysts):

**Data collection forms for Paper V****INFERTILE CASES****Previously performed investigations (if available)**

<b>ULTRASOUND?</b>	Yes	No
If yes, specify findings:		
<b>HSG?</b> If yes, specify below:	Yes	No
Right tubal blockage	Yes	No
Left tubal blockage	Yes	No
Other abnormal findings:	Yes	No
Specify:		
<b>HORMONAL PROFILE</b>	Yes	No
If yes, specify below:		
Test:	Result (normal/abnormal):	
<b>D &amp; C</b>	Yes	No
If yes specify findings:		

Information filled out by Dr..... date.....

**Laparoscopy**

Performed date:		by Dr:	
<b>Right tube</b>	patent	blocked	
	no adhesions	peritubal adhesions	
<b>Right ovary</b>	normal	abnormal	
<b>Left tube</b>	patent	blocked	
	no adhesions	peritubal adhesions	
<b>Left ovary</b>	normal	abnormal	
Other laparoscopy findings	Yes	No	
Specify other findings			
<b>CONCLUSION</b> tubal factor infertility	Yes	Possible	No
Comments			

**Laboratory investigations**

Investigation	result	date	signature
Hb			
Blood group			
Urine analysis	Pus cells RBC Albumine Glucose		
Urine deposits of ova bilharziasis	Yes	No	
<b>Semen analysis</b>	Normal	Abnormal	
Chlamydia serology	+ ve -ve	titer	
Gonorrhoea serology	+ ve -ve	titer	
Syphilis serology	+ ve -ve	titer	

**Treatment/referral**

Any treatment given for free based on laboratory findings?	Yes	No	
Diagnosis	Drug	Prescribed by	Date
Any Referral (for instance infertility clinic)?	Yes	No	
If yes, specify:	By Dr	Date	

**Complications**

Any complications due to laparoscopy?	Yes	No
Diagnosis:	Number of days admitted:	
Cause:		
Treatment		
Outcome:	Date/Dr	
Other complications:		

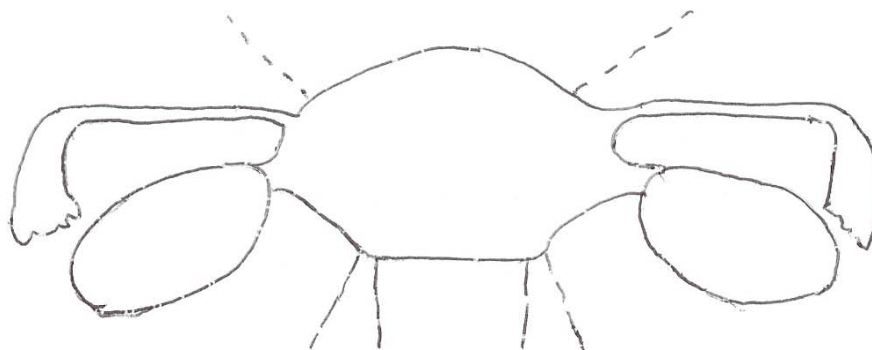
## Data collection forms for Paper V

Primary infertility in the young woman as a consequence of female genital mutilation in childhood  
University of Khartoum, Sudan and Karolinska Institutet, Sweden

### LAPAROSCOPY

Surgeon: \_\_\_\_\_ date: \_\_\_\_\_

Patient name: \_\_\_\_\_ Case number: \_\_\_\_\_ LMP: \_\_\_\_\_ Date of cycle: \_\_\_\_\_



Uterus: Shape: Size: Position: Abnormalities:

Adhesions: ☐ Yes ☐ filmy ☐ thin ☐ thick ☐ attached to:  
☐ No

Right Ovary: Shape: Size: Colour: Blood vessels:

Surface: ☐ smooth ☐ wrinkled ☐ Corpus luteum ☐ cysts

Right peri-ovarian adhesions: ☐ Yes ☐ filmy ☐ thin ☐ thick ☐ attached to:  
☐ No

Left Ovary: Shape: Size: Colour: Blood vessels:

Surface: ☐ smooth ☐ wrinkled ☐ Corpus luteum ☐ cysts

Left peri-ovarian adhesions: ☐ Yes ☐ filmy ☐ thin ☐ thick ☐ attached to:  
☐ No

Right Tube: ☐ patent ☐ blocked at ☐ cornual ☐ middle ☐ fimbria

Right adhesions: ☐ Yes ☐ filmy ☐ thin ☐ thick ☐ attached to:  
☐ No

Left Tube: ☐ patent ☐ blocked at ☐ cornual ☐ middle ☐ fimbria

Left adhesions: ☐ Yes ☐ filmy ☐ thin ☐ thick ☐ attached to:  
☐ No

Endometriosis: ☐ Yes ☐ No

Other findings:

Conclusion tubal factor infertility: ☐ Yes ☐ possible ☐ No

Comments:

**Data collection forms for Paper V****FERTILE REFERENTS**

REFERENT NUMBER:\_\_\_

Recruited from centre                      KTH                      Soba

Name

Age

Address

Phone

Religion

Tribe

Socio-economic level:                      low                      medium                      high

Total number of years in school (from primary including university):\_\_\_\_\_

Profession

Married since

Husband's age

Husband's total number of years in school (from primary including university):\_\_\_\_\_

Husband's profession

**Inclusion criteria (please tick:)**

Nullipara expecting first delivery

No prior problems in getting pregnant

\_\_\_\_\_

Information on this page filled out by Dr.....date.....

**History**

Circumcised?                      Yes                      No

Age at circumcision?                      \_\_\_\_\_                      If not certain range: \_\_\_\_\_

Reported form of circumcision                      Type 1                      Type 2                      Type 3                      Other

If other form, specify:

Fever after the circumcision?                      Yes                      No                      Don't remember

Seek medical care after circumci                      Yes                      No                      Don't remember

Admitted after circumcision?                      Yes                      No                      Don't remember

Cause of seeking care/admission:

History of UTI?                      Yes                      No

Number of UTI episodes?                      0                      1-3                      &gt;3

Age at menarche?                      \_\_\_\_\_

Kata                      ...../.....

Regular?                      Yes                      No

Primary dysmenorrhoea?                      Yes                      No

Secondary dysmenorrhoea?                      Yes                      No

Menorrhagia                      Yes                      No

Metrorrhagia                      Yes                      No

**Examination**

Weight: \_\_\_\_\_kg                      Height: \_\_\_\_\_cm

Gestational week: \_\_\_\_\_

Observed form of circumcision                      Type 1                      Type 2                      Type 3                      Other

<b><u>Anatomy:</u></b>	Untouched	Partially removed	Totally removed	Sides stitched together
Clitoris				
Labiae minora				
Labiae majora				

Other findings (e.g. fenestrations of infibulation, inclusion cysts):

Laboratory investigations

Investigation	result	date	signature
Hb			
Blood group			
Urine analysis	Pus cells RBC Albumine Glucose		
Urine deposits of ova bilharziasis	Yes	No	
Chlamydia serology	+ ve -ve	titer	
Gonorrhoea serology	+ ve -ve	titer	
Syphilis serology	+ ve -ve	titer	

Treatment/referral

Any treatment given for free based on laboratory findings?		Yes	No
Diagnosis	Drug	Prescribed by	Date
Any Referral (for instance TB-treatment, infertility clinic)?		Yes	No
If yes, specify:		By Dr	Date



## ***Informed consent Paper IV***

### ***Impact of FGM on the girl child***

A research collaboration between University of Khartoum, Sudan and Karolinska Institutet, Sweden.

#### **Informed consent**

##### **Information given in colloquial Arabic to parent/guardian:**

We would like to ask whether we may include your daughter/this child in research about different causes of emergency consultations in paediatrics. The overall aim is to be able to improve health care for girls. One of the things we will look into is if female circumcision is a risk factor for disease. Participation is fully optional, and the child will receive the same standard of care independent of your choice.

What will it mean to participate:

We will interview you for the history and examine the child as usual. History taking and examination will be more detailed than is normally the case. A full examination, including examining heart, lungs, abdomen and inspection of eyes, mouth and genitals will take place. Otherwise, you will notice no difference if you participate or not. We will record things from the journal, but we will not record the name together with the other things, so everything will be kept fully confidential. The child will be offered exactly the same investigations and recommended the same treatment as normally at this hospital, even if you choose not to participate.

The study will not lead to any increased risk for the child.

Again, we would like to stress that participation is voluntary.

The doctor verifies that informed consent was given by filling out and signing the data collection form.

## ***Informed consent forms for Paper V***

### Cases

## ***PRIMARY INFERTILITY IN SUDAN***

A research collaboration between University of Khartoum, Sudan and Karolinska Institutet, Sweden.

### Informed consent

We would like to ask whether we may include you in research about different causes of infertility, mainly whether female circumcision is related to infertility. The study will compare women who are under investigation for infertility with pregnant women. The aim is to identify risk factors for infertility so that these can be prevented in the future. If you participate we will keep everything confidential, and we will never reveal your name. Participation is fully optional, and you will receive the same standard of care independent of your choice.

What will it mean to participate:

We will perform the same investigations as would have been done otherwise. We will take blood samples and offer you to undergo laparoscopy, a surgical procedure where we will look at your internal genitals too see whether we can find any cause for the infertility problem. The blood samples will be stored for possible future use. If you participate, you will get the investigations for free. If we find any infectious disease you will get antibiotics for free. If we diagnose the cause of your infertility problem, we will NOT cover the treatment of this. That is, you will have to pay for any treatment of infertility yourself. We will pay only for the diagnostic procedures.

The study will not lead to any increased risk for you, since we do not perform anything extra just because of the study. However, there is always a risk to undergo surgery, for instance the risks of bleeding and infection.

Again, we would like to stress that participation is voluntary, and you will receive the same standard of care independent of your choice.

Would you like to participate?

The doctor verifies that informed consent was given by filling out and signing the data collection form.

## Referents

# *PRIMARY INFERTILITY IN SUDAN*

A research collaboration between University of Khartoum, Sudan and Karolinska Institutet, Sweden.

## Informed consent

We would like to ask whether we may include you in research about different causes of infertility, mainly whether female circumcision is related to infertility. The study will compare women who are under investigation for infertility with pregnant women like you. The aim is to identify risk factors for infertility so that these can be prevented in the future.

If you participate we will keep everything confidential, and we will never reveal your name. Participation is fully optional, and you will receive the same standard of care independent of your choice.

What will it mean to participate:

In addition to the routine blood samples taken in antenatal care, we will, at the same time, take some more blood. The blood samples will be stored for possible future use. If you participate, you will get all investigations for free, even the routine tests. If the tests reveal any infectious disease you will get antibiotics for free. The study will not lead to any increased risk for you.

Again, we would like to stress that participation is voluntary, and you will receive the same standard of care independent of your choice.

Would you like to participate?

The doctor verifies that informed consent was given by filling out and signing the data collection form.

## Sudan Village Concept Project Summary of achievements



<b>OBJECTIVES</b> (as stated in the project proposal)	<b>RESULTS</b> (according to the quantitative evaluation)
<i>- to equip and staff the health units of the area</i>	Fulfilled! Please refer to the table below and comments under heading 3.8.1.
<i>- to train at least one mid-wife/community health worker per village</i>	Not fulfilled. Please refer to comments under headings 3.6.1 and 3.6.2.
<i>- to achieve 95% immunisation coverage for the six killing diseases of childhood</i>	95% Fulfilled!
<i>- to train 90% of the mothers in proper management of child-diarrhoea</i>	88% Almost fulfilled.
<i>- to promote family planning</i>	There was a significant increase in knowledge and use of family planning. Fulfilled!
<i>- to significantly increase the attendance at antenatal care clinics</i>	There was an increase of the attendance at the antenatal clinics from 78 to 89% (non-significant). Not fulfilled.
<i>- to significantly increase the use of ORT against childhood diarrhoea</i>	A significant increase from 41,5 to 88%. Fulfilled!
<i>- to significantly decrease the use of channel water for drinking</i>	A drop from 93% to 66% (significant) (in times of power cut and fuel shortage; normally 99% had access to safe water after the project compared to 93% before the project). Fulfilled!
<i>- to ensure that at least 80% of the households have latrines</i>	87% have access to latrines. The project provided the area with 222 new latrines. Fulfilled!
<i>- to decrease the illiteracy rate by 50%</i>	Not fulfilled.
<i>- to increase the knowledge about zoonotic diseases</i>	A significant increase from 42 to 58%. Fulfilled!
<i>- to improve the knowledge about cleaning of animal places</i>	A significant increase from 23 to 38%. Fulfilled!
<i>- to make inspected meat accessible for the villagers</i>	The accessibility to inspected meat increased from 0 to 60 %. Fulfilled!
<i>- to increase the knowledge about proper use of liquid fertilisers and pesticides</i>	A significant increase from 15 to 40 %. Fulfilled!

***Sudan Village Concept Project  
Summary of achievements, continued***

***The situation at the health facilities before and after the project***

<b><i>Village</i></b>	<b><i>Pre intervention</i></b>	<b><i>Post intervention</i></b>
<b><i>Umdowina</i></b>	Dispensary, with deficient staff, shortage in equipment and drugs	Health centre with full staff, equipment and drug supply
<b><i>El Tiboob</i></b>	Health centre (less well equipped, shortage in drug supply)	A working health centre with much better equipment and drug supply
<b><i>Wad Kerai</i></b>	Not working dispensary	A working health centre with almost full staff, equipment and drugs
<b><i>Umjeloud West</i></b>	Not working dispensary	A working dispensary with full staff, equipment and drugs
<b><i>Umjeloud East</i></b>	No health unit	A working dispensary with full staff, equipment and drugs
<b><i>Najero</i></b>	Not working dressing unit	A working dispensary, but with deficient staff and poor equipment
<b><i>Fadleen</i></b>	Not working dressing unit	A working dispensary with full staff, some equipment and some drugs