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Global Perspective on Deinfibulation

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Global Development and Manage-
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Master´s Thesis
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Laurea University of Applied Sciences **Abstract**
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Female genital mutilation (FGM) causes many adverse physical, mental, sexual, and obstetric outcomes. Surgical deinfibulation is a procedure in which the sealed vagina opening is cut open, and thereby can ease the problems caused by FGM. One goal in National Institute for Health and Welfare's Action Plan for Sexual and Reproductive Health 2014 - 2020 is to increase research related to FGM. Finland does not have national guidelines concerning deinfibulation currently. Surgical deinfibulation after FGM is available but it has been too rarely used in Finland although it could reduce the negative impact of FGM.

The objective of this study is to seek evidence on deinfibulation related practices facilitating the guideline creation process of National Institute of Health and Welfare professionals working with women living with FGM. The research questions of this study are: 1. What are the factors facilitating or barring the use of deinfibulation? 2. What are the advantages and disadvantages of deinfibulation? 3. When is the ideal timing to undergo deinfibulation?

Integrative literature review was used as a method for this study. Data search was conducted in December 2017 by using five databases. After the evaluation process, 22 qualitative and quantitative studies with varying designs were included. Quality of observational studies was assessed with the help of STROBE, qualitative studies were assessed with the help of CASP and systematic literature reviews were assessed with the help of PRISMA. Evidence from the primary studies were extracted, analysed and synthesized by themes.

Women seek deinfibulation for various reasons, pregnancy and health problems caused by FGM being most prevalent. From a health care point of view, themes such as knowledge, management, experience, communication, and clarity and continuity of care were identified as barriers and facilitators. From the viewpoint of women living with FGM, several cultural factors, such as fear of not getting married, value of women's virginity and virtue, and the value of men's virility and sexual pleasure emerged from the evidence.

Deinfibulation appears to be a simple procedure with minor complication. Deinfibulation can reverse some adverse health outcomes caused by FGM such as painful periods, urinary tract infections, sexual problems, and obstetric problems such as caesarean section and perineal tears. Overall satisfaction for the procedure was good but part of the women have difficulties accepting the new body image after deinfibulation.

Deinfibulation performed before or during labour is comparable in the terms of obstetric outcomes although the trend was favourable on deinfibulation performed before labour. Women's preferences of the timing of deinfibulation differs, although most women seem to prefer to undergo deinfibulation during labour.

Identifying barriers and facilitators, information about the possible benefits and harms, and the best timing of the procedure guides professionals to design services that can respond the needs of women with FGM and supports the creation of practical guidelines. Evidence-based information is important when guiding the candidates for deinfibulation so that the woman can make informed choice of her care.

Keywords: female genital mutilation (FGM), deinfibulation, integrative literature review

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1 Introduction

Female genital mutilation (FGM) includes all procedures that intentionally cause injury to the female genital organs for non-medical reasons. This procedure has no health benefits and it harms women in many ways short-term and long-term. FGM occurs in all parts of the world, but it is most prevalent in the western, eastern, and north-eastern regions of Africa, some countries in Asia and the Middle East. (OHCHR et al. 2008, 1.) Deinfibulation is a procedure in which the sealed vaginal opening of a woman who has been infibulated is cut open. This is often necessary for improving the woman's health and well-being as well as to allow intercourse or to facilitate childbirth. (World Health Organization 2017b.)

From the beginning of the 1990, when Finland started to accept refugees from Somalia, FGM issues became timely in Finland for the first time (Ihmisoikeusliitto Ry 2004, 16). Since then, Finland's foreign population has been evenly growing, although it is still relatively low when compared to other European countries (Castaneda, Rask, Koponen, Mölsä & Koskinen 2012, 1). Due the increasing migration, FGM and issues related to it are current also in Finland. Information of women who have undergone FGM, or are at risk of FGM, are not systematically collected in Finland. There is a need for more and better data to plan prevention strategies and to ensure that the services meet the needs of women and girls affected by FGM. According to National Institute for Health and Welfare (Terveyden ja hyvinvoinnin laitos 2017), the majority of health care professionals in municipalities deal with issues related to FGM, but only a third have received training concerning FGM. Lack of experience or inappropriate training of health care professionals may lead to inadequate medical treatment of women with FGM during their pregnancy and birth care due to e.g. the ignorance of the deinfibulation technique (Chalmers & Hashi 2000, 227; Krása 2010, 269). It is also notable that women with FGM do not always recognise that some of the health problems they are suffering from are caused by FGM and this unawareness is an obstacle for seeking help, and it lessens the support for FGM prevention (Krása 2010, 277).

The idea to survey deinfibulation-related practices globally came from the authors´ personal interest on the topic and from National Institute for Health and Welfare. One goal in National Institute for Health and Welfare's Action Plan for Sexual and Reproductive Health 2014 - 2020 is to increase research related to FGM (Klemetti & Raussi-Lehto 2014, 83). Finland does not have national guidelines concerning deinfibulation currently. Surgical deinfibulation after FGM is available but it has been too rarely used in Finland although it could reduce the negative impact of FGM. In most cases, deinfibulation is done during childbirth by midwives currently. The Finnish Society of Obstetrics and Gynaecology and The Federation of Finnish Midwifes (2017) recently released a statement concerning the care of women who have undergone FGM.

They recommend that if the woman has health problems caused by FGM, or if she is pregnant, the care of the woman should take place in public health care. Additionally, if the girl or woman wants, she should be directed to a specialist so that the deinfibulation could be performed already before the girl or woman becomes sexually active. (Grénman & Rytkönen 2017.)

2 Female Genital Mutilation (FGM)

Female genital mutilation (FGM) or female genital cutting (FGC) includes all procedures that involve partial or total removal of the external female genital organs or cause other injury to the female genital organs for non-medical reasons. FGM is mostly performed on girls between ages of 0 and 15 years but occasionally the procedure is also performed on adult and married women. (OHCHR et al. 2008, 1.) Due to lack of a sufficient statistic, the exact number of girls and women worldwide who have undergone FGM remains unknown. It has been estimated that at least 200 million girls and women in 30 countries have been subjected to undergo such practice. Half of the girls and women who have undergone FGM live in three countries: Egypt, Ethiopia and Indonesia. (UNICEF 2016.) Due the rise in international migration, FGM has become an issue of increasing concern in host countries. Between 2011 and 2014, it was estimated that approximately 97,000 girls and women were at risk of FGM in Belgium, Denmark, Italy, Netherlands and United Kingdom (European Institute for Gender Equality 2015, 31). Many Western countries have introduced specific standards concerning FGM, e.g. legislations, recommendations on health promotion and the care of women who have undergone FGM (Krása 2010, 277). However, in many countries the systematic cooperation between the key players from grass root level to the health care sector is insufficient. Additionally, many health care professionals report that their knowledge and skills about how to care for girls and women suffering complications of FGM are insufficient. (World Health Organization 2010, 9-10.)

2.1 Classification of female genital mutilation

WHO/UNICEF/UNFPA 2007 joint statement classifies FGM originally in four types. After a decade using these classifications, a need to sub-divide these categories has arisen in order to get more accurate variety of these procedures. (World Health Organization 2016, 1-4.) Classification of FGM adapted from WHO is depicted in the Figure 1.

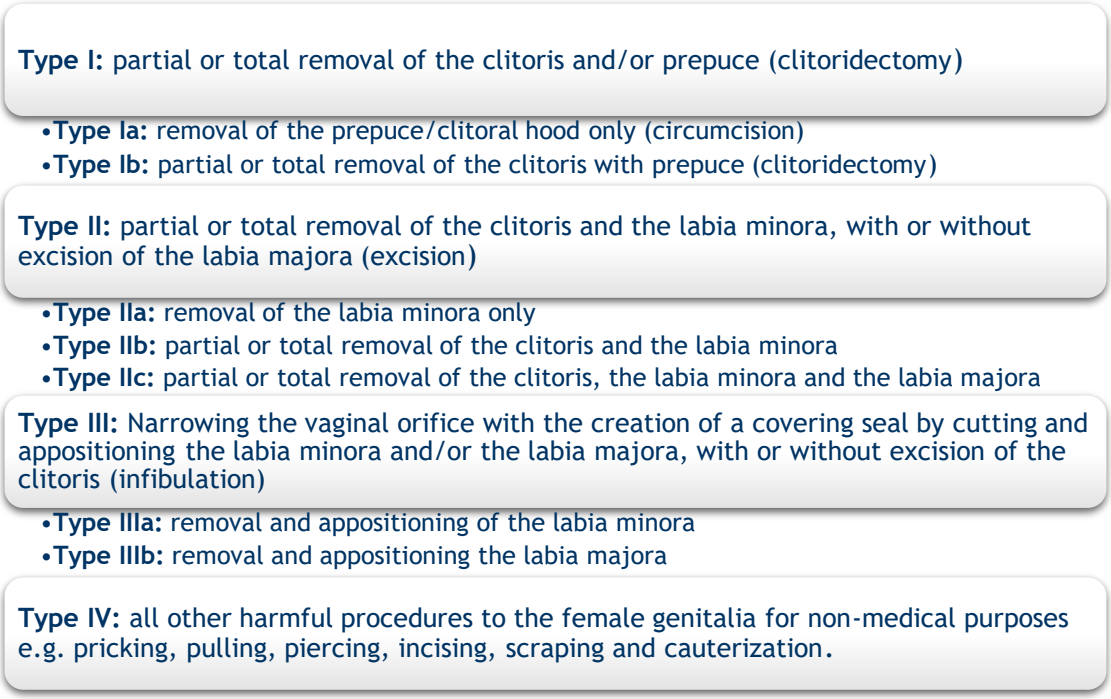

Figure 1: Classification of FGM adapted from WHO (2016)

2.2 Reasons why female genital mutilation is performed

The causes of female genital mutilation include a mix of a religious, cultural and social factors within the families and communities. From the social factors point of view, the social pressure to confront to what others do and have been doing, is a powerful motivation to carry on the practice. In many cultures, FGM is often associated as a necessary part of raising a girl properly and it is a way to prepare the girl for adulthood and marriage. In cultures where prevalence of FGM is high e.g. Somalia, the practice of FGM is an honoured tradition and there is a cultural stigma associated with those who are not circumcised. Parents may feel that the pain that their daughters experience during and after circumcision is a lesser evil than the emotional and economic hardship they will endure by remaining unmarried. (World Health Organization 2017a.)

Beliefs about what is considered to be proper sexual behaviour, such as premarital virginity and marital fidelity, for woman is often motivation to perpetuate the practice. In many communities, FGM is believed to reduce a woman's libido and therefore believed to help the girl to resist prohibited sexual acts. There are also beliefs that girls become clean and beautiful after removal of body parts that are considered male and unclean. No religious scripts prescribe the practice but often there is still belief that FGM has religious support. Local structure of

power and authority (community leaders, religious leaders, circumcisers, medical personnel) can promote maintaining the practice. (World Health Organization 2017a.)

2.3 Consequences of female genital mutilation

FGM has no known health benefits. There are several short-term and long-term risks related to FGM. Cutting the sensitive genital tissue causes extreme pain and proper anaesthesia is seldom used. (World Health Organization 2016, 1.) In most cases the procedure is being performed in unsterile conditions by a traditional practitioner who has little knowledge of female anatomy (UNICEF 2013, 42).

2.3.1 Physical consequences

Berg, Underland, Odgaard-Jensen, Fretheim and Vist (2014) systematically reviewed in their large study the physical health risks associated with FGM. Their systematic review provides clear evidence that FGM entails harm to women's physical health throughout their life. Most common procedure-related complications were haemorrhage, pain, urine retention, genital tissue swelling, infections and problems with wound healing. A few immediate deaths were also identified. FGM type III was related to greater risk of immediate harms than types I-II. Several long-term consequences of FGM were found. These consequences include increased risks of urinary tract infections, bacterial vaginosis, painful intercourse and obstetric complications. (Berg et al. 2014, 4-9.)

2.3.2 Consequences on mental health, social life, and sexuality

The psychological, social and sexual consequences of FGM are under-researched and overlooked issue. The low quality of the evidence and the lack of a unified approach and definitions to measure e.g. sexual functioning precludes drawing solid conclusions in many cases. (Berg, Denison & Fretheim 2010, 6; Berg & Denison 2012, 54.) FGM is a strongly traumatic experience which can leave a long lasting psychological mark and affect injuriously on mental health. Women with FGM may have various emotional and psychosocial difficulties e.g. posttraumatic stress disorder, anxiety, somatization phobia and low self-esteem. (Berg et al. 2010, 49; Mulongo, Martin & McAndrew 2014, 469.)

There is not much research of what kind of a role FGM plays in the social lives of women. Childbirth can activate the negative feelings that FGM has caused (Vloeberghs, Kwaak, Knipscheer & Muijsenbergh 2012, 677). There seems to be a significant difference in marital satisfaction between women with FGM and without FGM. FGM can be a basic factor in marital dissatisfaction as it can cause sexual dissatisfaction and mental health problems which play a significant role in marital satisfaction. (Koolaee, Pourebrahim, Mohammadmoradi & Hameedy

2012, 115.) It is noteworthy that migration makes women with FGM more aware of their condition and it can cause sense of shame. Feeling ashamed occurs e.g. when being examined by a physician which can lead to avoiding visiting health care services and eventually complicate the woman's state of health. (Vloeberghs et al. 2012, 677.)

Berg and Denison's (2012, 54) systematic review of the sexual consequences of FGM substantiates the presumption that a woman who has undergone FGM is more likely to experience increased pain and reduction in sexual pleasure and desire. Any type of mutilation of critical genital tissues causes scar formation and reduce its flexibility and sensitivity and therefore it may cause pain during intercourse. Type III FGM creates a mechanical obstruction for intercourse and infibulation through penetrative sex may cause frequent pain for the women. (Berg & Denison 2012, 50.)

Women with FGM have reduction in all aspects of sexual function: sexual desire, sexual arousal, lubrication, orgasm, satisfaction, and pain when compared with women without FGM (Mahmoud 2016, 57; Rouzi et al. 2017, 1; Ismail et al. 2017, 5). The study of Rouzi et al. (2017, 1) indicates that the sexual dysfunction is significantly greater with a more extensive type of FGM. FGM may also cause male sexuality-related complications e.g. difficulty in penetration, wounds, bleeding, infections of the penis and psychological problems (Berg & Denison 2012, 52).

According to the studies, women with FGM are less likely to experience orgasm. However, humans' sexuality is a complex mechanism and sexual pleasure and satisfaction comprises more than just genital organs. Cultural influence and social acceptance can change the perception of pleasure. Women with FGM can have the possibility to experience orgasms, and sexual dysfunctions can be treated with appropriate sexual therapy. (Catania et al. 2007, 1666.)

2.3.3 Consequences on pregnancy and labour

FMG is a risk for pregnancy and labour especially in the developing countries where women have poor obstetric outcomes for multiple reasons. Although many pregnancies are low risk and non-interventional in Western countries, FGM does have a significant impact on a woman's obstetric outcomes also in the Western world. (Gayle & Rymer 2016, 980.)

Miscarriage is a common event especially in early pregnancy. Women with FGM, especially with type III as they have a small vaginal orifice, may face problems in the event of miscarriage. The small vaginal opening can make monitoring the progress, surgical and medical management of the miscarriage difficult or even impossible. FGM increases the risk of retained products of conceptions, pelvic infections and vaginal infections. (Gayle & Rymer 2016, 981.)

Urinary tract infections (UTI) are the most common bacterial infections during pregnancy (Le, Briggs, McKeown & Bustillo 2004, 1695). Studies have shown that women with FGM are in greater risk for having UTIs (Berg et al. 2014, 9). UTIs and acute antepartum pyelonephritis are proven to be associated with adverse perinatal outcomes, and it is an independent risk factor for preterm delivery, intrauterine growth restriction and low birth weight (Farkash et al. 2012, 26). Catheterizations are sometimes required during the delivery and obscured urethra due to FGM complicates the treatment of the woman (World Health Organization 2000, 17; Gayle & Rymer 2016, 981).

The difficulty in performing vaginal examinations during the pregnancy or delivery on women who have undergone FGM, is a risk factor because it can generate delay in the diagnosis of obstetric complications and result in delayed treatment (Gayle & Rymer 2016, 981). All types of FGM can cause risk for prolonged and obstructed labour (World Health Organization 2000, 19). Women with type III FGM have a significantly higher risk of need for episiotomy performed during the delivery. The risk for episiotomy is higher especially in primiparous women but also in multiparous women. (World Health Organization 2006, 1838; Berg et al. 2014, 9.) The risk for perineal tears is also higher in women with FGM (Kaplan, Forbes, Bonhoure, Utzet, Martin, Manneh & Ceesay 2013, 326). Research results concerning the increased risk for caesarean section in women with FGM are currently contradictory. WHO (2006, 1838) study indicates that the risk is increased but Berg et al. (2014, 9) did not find strong connection between FGM and caesarean section.

Postpartum haemorrhage is a significant cause of maternal deaths globally (World Health Organization, 2012, 1). According to WHO's (2006, 1839) large prospective study, the deliveries of women with FGM were more likely to be complicated by postpartum haemorrhage than women without FGM. Mahmoud's (2016, 55) case-control study resulted that FGM is a risk factor for obstructed labour and postpartum haemorrhage. The risk for having extended maternal hospital stay, resuscitation of the infant, and inpatient perinatal death are also significantly higher in women with FGM. The risk for obstetric problems was greater with more extensive FGM. (World Health Organization 2006, 1839.) The study of Kaplan et al. (2013, 329) indicates that FGM has a strong relationship with fetal complications; FGM was linked with higher risk of fresh stillbirth, fetal distress and caput of the fetal head.

2.4 Female genital mutilation and human rights

FGM is a global concern and a global human right issue affecting girls and women in every region of the world. Such practices reflect deep-rooted inequality between the sexes, and it establishes an extreme form of discrimination against women. FGM is mostly performed on children and therefore it is a violation of the rights of the child. FGM practice violates also

several other human rights: security and physical integrity of the person, the right to health, the right to be free from torture and cruel, inhuman or degrading treatment, and the right to life when FGM results in death. (OHCHR et al. 2008, 1.)

In September 2015, The United Nations agreed to 17 development goals – The Sustainable Developments Goals (SDGs) (United Nations 2015). Under the Goal 5 – Gender Equality – the goal is to eliminate all harmful practices, such as child, early and forced marriage and female genital mutilation by the year 2030. The rates of female genital mutilation have been declining over the past three decades but not all countries have made progress and the pace of decline has been uneven. (United Nations 2016.)

3 Deinfibulation

Deinfibulation is a minor procedure carried out to open the sealed vaginal opening in women living with type FGM III (World Health Organization 2016, 8). Sometimes deinfibulation is termed as a "reversal" of FGM which is misleading as it cannot restore the genital anatomy and function of how it was before FGM. Deinfibulation can be performed by a physician at outpatient clinic usually under local anaesthetic. Sometimes general or spinal anaesthetic is needed. (Royal College of Obstetrician and Gynaecologists 2015, 15.) More common is that the deinfibulation is performed during childbirth by a midwife or obstetrician to facilitate childbirth and to avoid uncontrolled tearing (Johansen 2017a, 4). Deinfibulation is performed by an incision of the midline scar tissue that covers the vaginal orifice until the external urethral meatus and clitoris are visible. The edges of the cut are sutured which allows the vaginal introitus to be stay open. (World Health Organization 2016, 8.) The main principles of deinfibulation are to identify key anatomic structures involved, execute appropriate anaesthesia, enhance exposure and minimize tissue trauma. It is important to protect the midline structures like cervix, urethra and clitoris when separating the underlying fused labia as labia. (Anand, Stanhope & Occhino 2013, 986.)

Deinfibulation is recommended for women whose introitus is not sufficiently open due to FGM to permit normal functions such as urinary and menstrual flow. The purpose of deinfibulation is to improve the health and well-being of the women living with FGM type III as well as to allow intercourse. It also facilitates medical examinations and childbirth. (Royal College of Obstetrician and Gynaecologists 2015, 15; World Health Organization 2016, 8). Sometimes deinfibulation is necessary to perform to permit cervical smears, gynaecological surgery and sexual health screens (Royal College of Obstetrician and Gynaecologists 2015, 15). Women who have undergone FGM do not always know about the possibility of deinfibulation. In some countries, deinfibulation is marked as cosmetic surgery rather than a therapeutic procedure. (Abdulcadir, Boulvain & Petignat 2012, 90-91.)

4 Goals, objectives and research questions

The goal of this research is to increase awareness of deinfibulation related practices globally to improve equality and the health status of women with FGM. The objective of this study is to seek evidence facilitating the guideline creation process of National Institute of Health and Welfare for professionals working with women who have undergone FGM.

The research questions for the integrative literature review:

1. What are the factors that facilitate or act as barriers to the use of deinfibulation?
2. What are the advantages and disadvantages of deinfibulation?
3. When is the ideal timing to undergo deinfibulation?

5 Data and methods

The study process started in March 2017 by choosing the topic and the method. Both authors shared the same interest on the topic and had a practical experience of the FGM and deinfibulation from their personal working life at different levels of the health care sector. The first author has almost a decade of experience in the Helsinki University Hospital working as a midwife in antenatal and delivery ward, and the experience has shown some gaps in treatment related to FGM and deinfibulation. The second author has experience from maternity and child health clinics working as a public health nurse and has also been working passionately for years with FGM related issues.

Finland is lacking the national guidelines concerning the deinfibulation. There are also shortcomings in health care districts' own guidelines and recommendations for health care professionals on how to treat women with FGM. For example, at the time this study was started, the Helsinki University Hospital (HUS), was lacking instructions for midwives of how to perform deinfibulation during labour, although it is the most common time when the deinfibulation is performed. Additionally, the guidelines for physicians on how to care for women with FGM were missing. When this deficiency of guidelines was discussed with the head physician of gynaecology of HUS, the lack of evidence was mention to be the main reason. About the same time, the second author contacted the National Institute for Health and Welfare to get ideas for the viewpoint for this study. They also suggested that it would be important to review the evidence relating to deinfibulation.

Integrative literature review was chosen as the research method for this study because of its potency to get comprehensive view of the topic being studied. The study was finalized in April 2018, and the thesis was done mainly on "leisure time" as a part of authors' Master studies,

both authors working at the same time full time in their own workplaces. A more accurate timetable is presented in Appendix 1.

5.1 Integrative literature review as a research method

Literature is an essential part of research studies. Often it is being used as a part of a study but it can also be used as a method for the whole study. Basically, literature review is a secondary research method that uses primary research to identify, evaluate, and interpret available research for a focused clinical question. (Holly et al. 2012, XV.) The main reason for choosing the literature review as a method for this thesis was the presumption that deinfibulation related practices have not been systematically studied in Finland. It is necessary to review this subject as it can help direct future theoretical study as well as identify the gaps in the current research. Well-done literature review of deinfibulation can provide a summary of research findings available and therefore it has greater validity than a single research study.

Literature review is not just a list of earlier research findings but it helps to clarify how the chosen topic has been examined earlier and what kind of evidence the researches have produced (Holopainen, Hakulinen-Viitanen & Tossavainen 2008, 73). To conduct a well-done literature review is not an easy task. Well-done review requires thorough search to identify relevant issues. The search process should be as transparent as possible and it must be documented carefully so that it is possible to evaluate and reproduce. (CRD 2009, 16.) Combining the evidence of multiple primary studies is a complex task. Cornerstones of the well-done review are clearly defined problem(s), purpose, and method. The quality of the primary studies must be evaluated properly and incorporated in the analysis and interpretations of findings. (Whittemore 2005, 61.) Health care is shifting from expert-driven health care to evidence based health care. Currently there is no evidence-based guideline concerning deinfibulation in Finland. Well-done literature review can be an efficient mean to advance clinical practice toward evidence-based care (Holly et al. 2012, XVI).

Integrative literature review is a distinctive form of review that generates new knowledge about the topic reviewed. Well-done integrative review indicates the state of science of chosen topic, connive to theory development, and have direct feasibility to practice and policy. (Whittemore & Knafl 2005, 546). Integrative literature reviews are the broadest types of research reviews, and they can include either empirical or theoretical literature or both, depending on the purpose of the research. One of the most prominent advantages of the integrative review approach is the capability to merge data from different types of research designs. Although merging the data from multiple research designs can be challenging in the analysis phase, it has a great potential to increase the depth of conclusions. (Stolt et al. 2015, 13; Whittemore 2005, 57.)

Whittemore (2005, 58) has introduced five stages of integrative review which have been originally modified from Harris Cooper's paper (2008). The stages are: a problem formulation stage, a literature search stage, a data evaluation stage, a data analysis stage and a presentation stage (Figure 2).

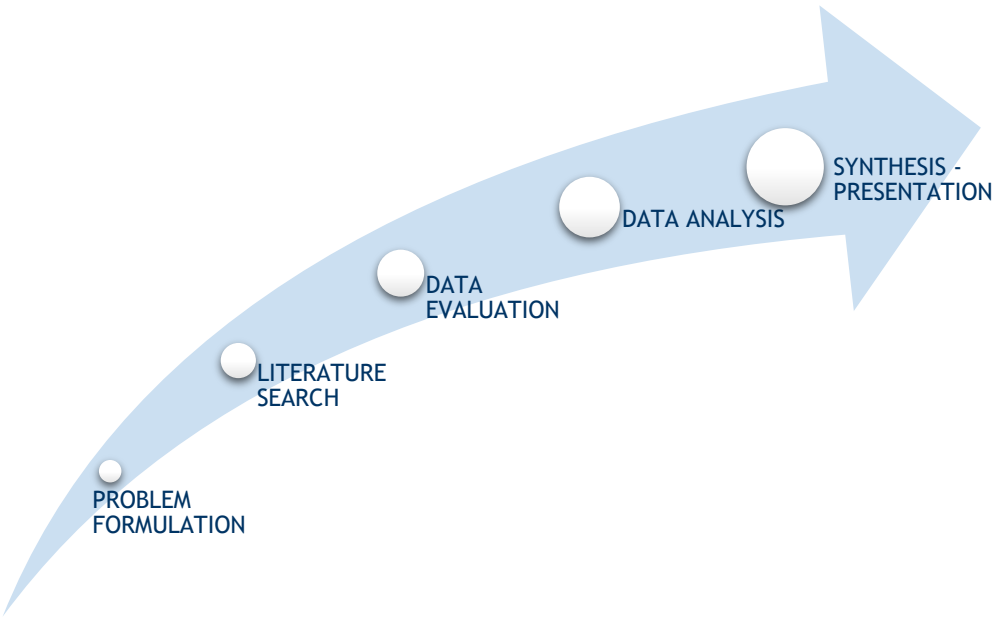

Figure 2: Five stages of integrative literature review from Whittemore (2005) modified by the authors

In the problem formulation stage, the clear identification of a problem and its association to the review purpose is important. A well-specified review problem and purpose will facilitate all other stages of the review. (Whittemore & Knafl 2005, 548.) Well-defined literature search strategies are essential to conducting a quality literature review (Whittemore 2005, 58; Conn et al. 2003, 178). Poorly made and biased searches will result in a deficient database and possibly faulty conclusions (Conn et al. 2003 181, 182).

After the relevant literature have been collected, the next stage is the data evaluation stage. The purpose of a data evaluation stage is to critically evaluate the primary studies. Due the differing design of the studies, the evaluation process in an integrative review is complex and there is no gold standard for evaluating and interpreting quality research reviews. Ideally, the data evaluation in an integrative review is addressed in a meaningful way. If the review data includes both theoretical and empirical sources, two types of quality criteria instruments could be used as criteria for inclusion/exclusion. (Whittemore & Knafl 2005, 549-550.) The reliability

of the review evaluation is increased if there are two individual reviewers (Whittemore 2005, 59).

The fourth stage of integrative literature review is the data analysis stage. The purpose of this stage is to organize, summarize and integrate a conclusion about the research problem. Data analysis techniques and procedures vary depending on the type of the research review. All reviews except meta-analysis use a narrative or qualitative analysis. This means that the researcher will compare the coded data from the individual studies with all the other studies for similarities or differences around variables of interest. In the end, the researcher will write a synthesis of the findings. Synthesis is the highest level of abstraction and it presents a new model or framework for the problem. (Whittemore 2005, 60; Whittemore & Knafl 2005, 550.)

The final stage is the presentation stage. In the final report, the literature search process should be clearly documented. The whole review process and results must be presented in detail so that the reader can easily evaluate the trustworthiness of the work. The report should include the search terms, the databases used, the search strategies, and the inclusion criteria for determining relevant studies (Whittemore 2005, 59). Ideally, the results will produce a new understanding of the reviewed topic and implications to the practice should be emphasized for example in additions to implications for research and policy initiatives. (Whittemore 2005, 61; Whittemore & Knafl 2005, 552.)

5.2 Inclusion and exclusion criteria

Inclusion and exclusion criteria were defined before the data search with mutual understanding. Inclusion criterions were defined to be broad as possible in order to find all the relevant studies. Peer reviewed original studies with all study designs were accepted. The study population was women who have undergone FGM and/or deinfibulation and their spouses. Additionally, professionals treating women with FGM were included. The year of the publication was not limited. The "grey literature" was excluded as we wanted to conduct high-quality study. The publication language was limited to English or Finnish. The inclusion and exclusion criteria are seen on Table 1.

INCLUSION CRITERIA	EXCLUSION CRITERIA
• Publication language: English or Finnish. • Study population: women undergone FGM and/or deinfibulation and their spouses and including professionals treating women with FGM. • Data type: peer reviewed original research (qualitative, quantitative, and mixed methods, systematic literature review, integrative literature review), peer reviewed conference abstracts, guidelines/recommendations for health care professionals. • Intervention: deinfibulation.	• Letters for editor, textbooks, pro-gradu thesis and narrative literature reviews, case reports. • Other languages.

Table 1: Inclusion and exclusion criteria

5.3 Data search and review

The data search for the study was performed in December 2017. After careful consideration and discussion and guidance from Terkko Health Hub information service, five databases were chosen for the data search (Figure 3). To ensure reliable data search, the search was made both independently and together by the authors.

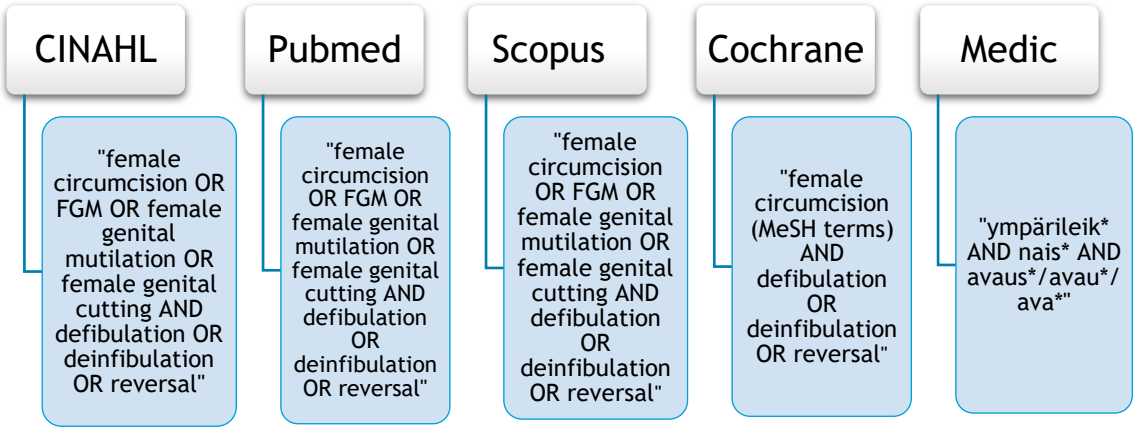

Figure 3: Data search from databases

All the references were stored in RefWorks software for closer review. In the first stage, all duplicates were removed. In the second stage title, abstracts and the study language were screened first individually by both authors and then together. After a consensus discussion in

January 2018, relevant references were chosen for full-text review. In the third stage the full-text of the articles were screened again first individually by both authors and then together until we reached mutual understanding. In the last stage, the chosen articles' full-text were assessed for inclusion criteria and quality first individually by both authors. Appropriate assessment tools for the references were chosen together at this point and both authors participated in the assessment tools development. After individual assessment, the results were compared. Compromises were made on the basis of reasoning in the cases of difference in scoring. After a consensus discussion in February 2018, the final references were included.

5.4 Quality assessment

The assessment of the validity of the included studies is an essential component of a literature review (Higgins & Greene 2011, 188). There are multiple different assessment criteria tools for different study designs (Higging & Greene 2011, 187; ICMJE 2015). The purpose of assessment criteria tools is to help researchers to report important points of the study methods, context of the study, findings, analysis and interpretation in a transparent way (ICMJE 2015; The Joanna Briggs Institute 2014, 13; Tong, Sainsbury & Craig 2007, 349). It is desirable that two review authors should independently assess the study quality and ensure that they have adequate understanding of the relevant issues (Higgins & Greene 2011, 192).

The Cochrane Collaboration has created A Handbook for Systematic Reviews of Interventions. According to them, the validity of studies can be considered to have two dimensions: external validity and internal validity. External validity is whether the study is asking an appropriate research question and its assessment depends on the purpose for which the study will be used. External validity is also connected with the generalizability of a study's findings. Internal validity relates to whether the study answers its research questions in a manner free from bias. A bias can be described as a systematic error in results of inferences which can lead to either an underestimation or an overestimation of the true intervention effect. (Higgins & Greene 2011, 188.)

The quality of the included studies was carefully assessed. It is typical for integrative review to have different study designs included which makes the evaluation process challenging (Whittemore & Knafl 2005, 549). To conduct the most desirable quality assessment, quality of the included studies was assessed by using three appropriate assessment tools: STROBE, PRISMA and CASP.

Many of the medical studies are observational. The reporting of observational studies may be of poor quality which weakens the generalizability of its results. STROBE is an assessment tool developed for strengthening the reporting of observational studies in epidemiology.

(Vandenbroucke et al. 2007, 1628.) The checklist (A) applied from STROBE was used to assess the quality of observational studies (Appendix 3).

Critical Appraisal Skills Programme (CASP) checklist for qualitative studies was used as an assessment tool for qualitative studies. CASP has several checklists for different study designs and the checklists were originally developed to be used as educational pedagogic tools and therefore it does not suggest a scoring system (CASP 2017). Nevertheless, a modified CASP checklist (B) for qualitative studies was used by adding scores so that it is in the same line with other assessment tools (Appendix 4).

PRISMA is an evidence-based checklist for reporting in systematic reviews and meta-analyses. PRISMA aims to improve the reporting of the systematic reviews and it can also be useful for critical appraisal of published systematic reviews but it is not an actual quality assessment tool for validating the quality of a systematic review. (PRISMA 2015.) However, the use of PRISMA may strengthen the methodological quality and reliability of systematic reviews (Moher et al. 2015, 8). A checklist (C) for quality assessment for these studies with the help of PRISMA (Appendix 5) was generated.

Scoring is commonly used in quality assessment checklists. Scoring was used, but the percentages were also added in this study so that the comparison of quality between different designs of studies would be easier. The quality of the observational studies was mainly moderate or high (59%-100%; mean 81%), although the quality of the evidence in many studies was assessed to be low because of the nature of an observational study design or combination of risks of bias. Nevertheless, the strength of observational study design is its ability to increase in-depth understanding. The quality of systematic reviews was mostly high (91-100%; mean 89), only one systematic review was assessed to be moderate (67%). The quality of the qualitative studies was generally high (80%-100%; mean 96%). For the one qualitative evidence synthesis paper included in this study, it was not meaningful to create a separate assessment checklist. Additionally, methods for assessing qualitative evidence synthesis findings are poorly developed (Lewin et al. 2015). CASP was chosen to use as a assessment tool for that study although the study design did not apply some of the assessment criteria. According to CASP, the quality of the study was assessed to be moderate (67%). The information of the search strategy, the characteristics and the assessment of the included studies were missing from the paper, which reduced the quality of the study.

5.5 Data analysis

Data analysis with integrative reviews means that the assorted data is compared item to item so that similar data is categorized, grouped and coded together. The coded data is compared further in the analysis and synthesis process. The data analysis stage is the most difficult aspect in the review and potentially prone to errors. Whittemore and Knafl have proposed an analysis method for integrative reviews to enhance the rigour of combining diverse methodologist data. (Whittemore & Knafl 2005, 546-550.) In this study, the data analysis started after the final studies were included and assessed. The data analysis was performed with the method applied from Whittemore and Knafl (2005, 549-551) (Figure 4).

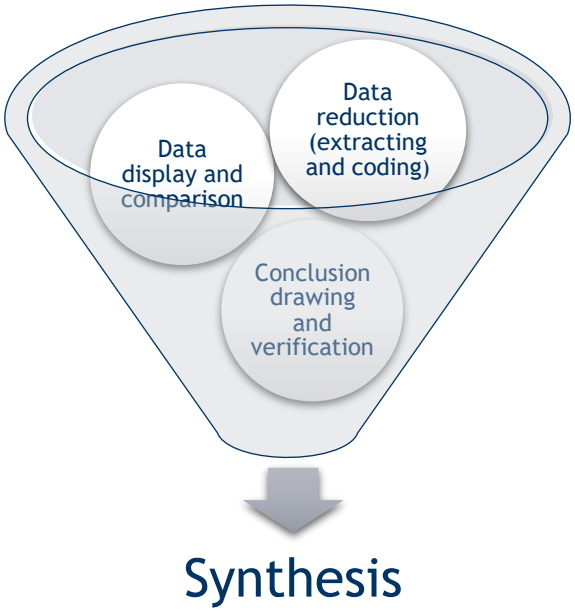

Figure 4: Integrative review data analysis process from Whittemore and Knafl (2005) modified by the authors

In the first stage, all studies were read repeatedly individually by both authors seeking answers to research questions by underlining the sentences. The characteristics of included studies were collected in the table (Appendix 2). That was followed by the data reduction as the evidence from the primary studies was extracted, and the data display spreadsheet was developed to facilitate appraisal and comparison. Data were organized, coded and categorized by themes. The next stage was data comparison in which the data display spreadsheet was examined to identify patterns and relationships. Primary sources were critically reviewed as the new data were integrated into the findings of this integrative review prior to making synthesis. Descriptive data of the studies are presented in the in the table in Appendix 1. The results were written out and discussed on the basis on research questions and themes. Strengths and

limitations of this study were discussed and implications for practice and future research were suggested. The analysis process is presented in Figure 5.

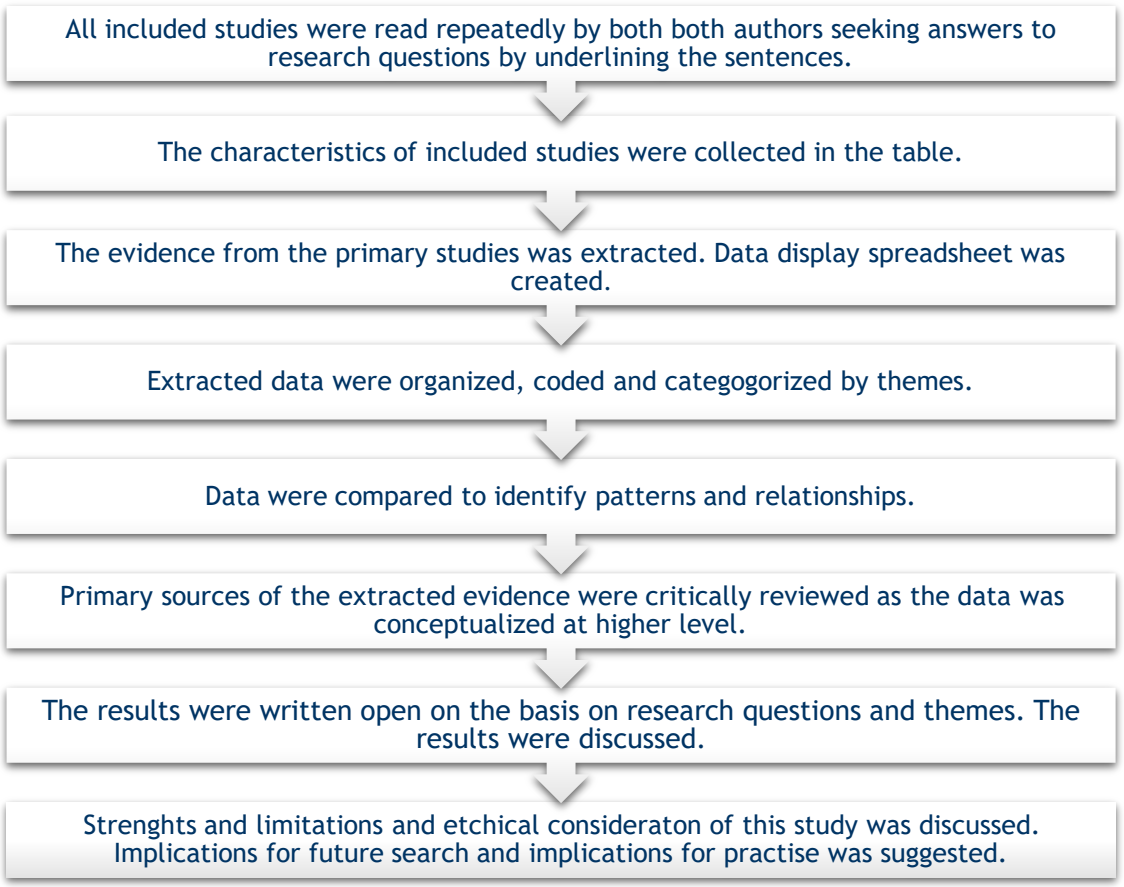

Figure 5: The data analysis process

6 Results

The data search output identified in total 222 references. After removing duplicates, 133 potential references were left for closer screening. First, the titles and abstracts were screened for relevancy, resulting in reducing the number of references to 66. Full text of the 66 references were reviewed, further narrowing the selection to 29 references. In the final step, the references were assessed for inclusion and exclusion criteria, as well as the quality. After the review process, in total 22 references were included in this study. The review process is decipted in Figure 6. The most frequent reasons for rejecting the articles were that they were a duplicate of an article found in another database, the topic was not the focus of this review, they were narrative reviews, or because the study did not have eligible studies included. No articles were removed because of the low quality of the article.

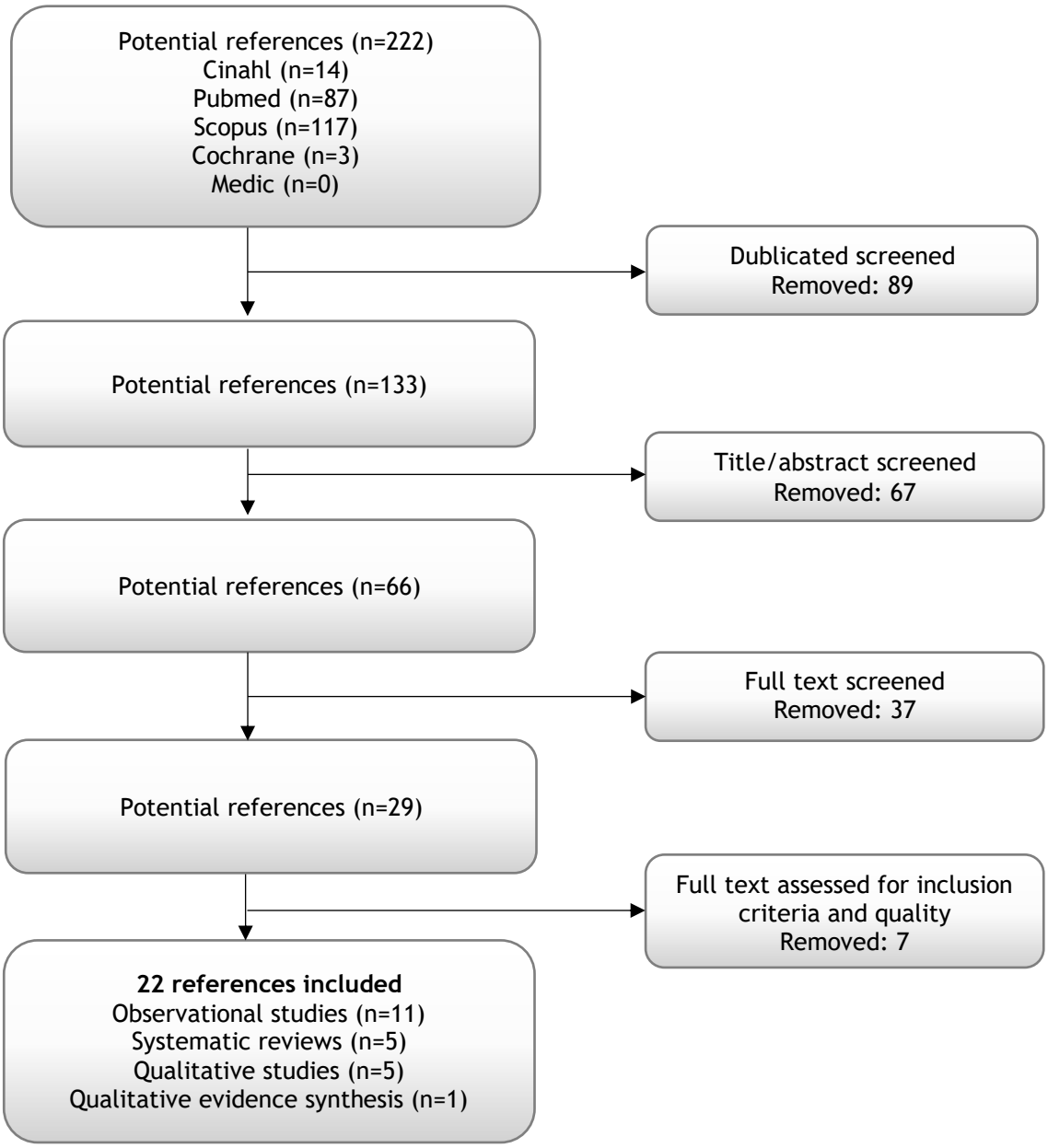

Figure 6: Data review process

6.1 Description of the included studies

Of the 22 included studies, eleven were observational studies, five systematic reviews, five qualitative studies, and one qualitative evidence synthesis. All of the studies were conducted in the 2000s, and almost half (45%) were conducted in the last two years, which makes the evidence quite up to date. Most of the studies were completed between 2015 and 2017 (n=10). In years 2001-2003, 2006-2009 and 2011-2014 four studies were published respectively. The settings of the studies were mostly in Western countries (86%). Studies were published in UK

(n=9), Norway (n=4), Switzerland (n=3), Italy (n=2), Saudi-Arabia (n=2), USA (n=1) and Nigeria (n=1). Although the settings of the studies were mostly in Western countries, the majority of the participants in the studies, with the exception of the health care personnel, were originated from countries where FGM is commonly practiced. Somalia was mentioned to be the most prevalent country of origin in thirteen studies. Other countries of origin mentioned were mostly other African countries.

6.2 Factors that facilitate or act as barriers to use of deinfibulation

Women requested deinfibulation for various reasons. In most studies pregnancy was the primary motivation for consultation and seeking deinfibulation to assist delivery of the baby during childbirth (Abdulcadir, Dugerdil, Yaron, Irion & Boulvain 2015, 175; Momoh, Ladhani, Lochrie & Rymer 2001, 189; Nour, Michels & Bryant 2006, 57; Penna, Fallani, Fambrini, Zipolli & Marchionni 2002, 1552). Other significant reasons for seeking deinfibulation were FGM related complications and health problems such as urinary tract infections, painful periods or menstrual cramps (dysmenorrhea), difficult or painful sexual intercourse (dyspareunia), inability to perform sexual intercourse as a result of a physical or psychological sexual dysfunction (apareunia), and difficulty urinating (Abdulcadir et al. 2015, 175; Berg, Taraldsen, Said, Sørbye & Vangen 2017a, 983; Catania et al. 2007, 1670; Johansen 2017b, 537; Momoh et al. 2001, 189; Nour et al. 2006, 57). Other reasons were that the woman was getting married, excision of cyst, cystic bulge, or swelling, discomfort, wish to improve fertility, sexual aspiration, aesthetic aspirations, and aspiration identity to recover (Berg et al. 2017a, 985; Momoh et al. 2001, 189; Nour et al. 2006, 57).

6.2.1 Health care workers lack of knowledge and experience

Studies conducted in Norway (Smith & Stein 2017) and Switzerland (Abdulcadir, Rodriguez, Say & Rodriguez 2014) described significant gaps in health care professionals' awareness of the prevalence, diagnosis and management of FGM. Some professionals have difficulties in identifying and classifying FGM according to WHO classification, as well as having lack of knowledge in recommendations of the clinical management and legislation on FGM. FGM is not often part of health care professionals' curriculum and due to that, the lack of knowledge, and lack of adequate skills to perform deinfibulation, have resulted to "improvisation", and variety of solution for managing delivery for women with FGM. (Abdulcadir et al. 2014, 298-299; Smith & Stein 2017, 44.) Due to the lack of familiarity with the procedure, and despite of the national guidelines, some health care workers are being resistant of cutting infibulated women and avoiding the deinfibulation thinking that it is too difficult or too risky. As a result, in some cases, caesarean sections are performed or even multiple episiotomies are used to avoid deinfibulation. Some health care workers do not consider it necessary to check if the woman

needs to be deinfibulated seeing that to be too intrusive. Evidence also suggests that immigrant women with FGM do not receive adequate care which heightens their anxiety. Women have described to be fearful that providers are lacking experience dealing with FGM especially during labour. (Smith & Stein 2017, 44-45.)

6.2.2 Culturally sensitive care and challenges in communication

Culturally sensitive care can be both an obstacle as well as it can be a facilitator. Moxey & Jones (2016, 5) described in their study that women were pleased that midwives gave them treatment options which respect their cultural and religious beliefs. In this case women were given a choice over when they wanted to undergo deinfibulation. Contrarily, in Smith & Stein (2017, 44) study culturally sensitive care was described as an obstacle. When asked reasons for avoidance of use of deinfibulation, the most frequently reported reason was ”a culturally sensitive care”. From their point of view, culturally sensitive care meant avoiding any cutting assuming that it is what the women also wanted. The truth was contrary in this case; women were feared not being deinfibulated. An additional reason described for avoidance of the procedure was the view that delivering women with FGM are “chaotic” or “out of control”, and that Somali women are more expressive and showing more pain during delivery. Hospital staff did not see the labour to be the right moment to discuss about FGM. Health care workers also tend to so blame women’s language difficulties or level of understanding, as the communication takes too much time. (Smith & Stein 2017, 44.)

Lack of communication between health care professionals may lead to health care workers’ poor management, and care of women with FGM. A study conducted in Norway (Smith & Stein 2017) revealed a communication gap between the outpatient clinic and hospital. Clinic personnel considered discussion of deinfibulation to be the duty of the hospital, but the hospital staff considered is a part of the clinic’s prenatal program. Study also reported that poor communication and coordination of responsibilities between different departments in the care of women with FGM will lead to less optimal care. Among health care workers there is unawareness of policies to identify women with FGM as well as lack of instructions how and when these women should be informed, or which information is important. Poor communication and problems with continuity of care also affects negatively on women’s experience of care in maternity services. In the countries where the FGM is not so prevalent, health care providers are unprepared and have a lack of capacity to discuss FGM related issues which will affect women’s experience of care in maternity services. Although the women expected health care professional to talk about the FGM and deinfibulation during prenatal care, this was not always the case. Study described this communication gap as “a deafening silence” which is ineffectual both for health care workers as well as for the women. With proper communication, health care professionals could get vital information about the fears and needs of women with FGM,

and mutually women would have an opportunity to have a clearer picture of their own situation, their care, and options for treatment. (Smith & Stein 2017, 44-45.)

6.2.3 Cultural factors

Several cultural factors emerged from the studies. In many cases, surgical deinfibulation is resisted because it is challenging the cultural values that underlie the practice (Johansen 2017a, 10). Fear of exclusion from own community is a strong fear that prevent women from undergoing deinfibulation although it would be medically advised (Abdulcadir et al. 2014, 300; Catania et al. 2007, 1674). Deinfibulation is strongly related to sexuality and sexual organs which make the issue deeply personal and the shadow of secrecy lies upon it (Safari 2013, 156). Deinfibulation is an issue which is not often discussed not even with close family or friends or sometimes not even with their husbands (Nour et al. 2006, 58; Safari 2013, 156). Feelings such as shame, disgrace, feeling that other would not understand, privacy, fear of being rebuked, fear of parents' disapproval and will of protecting their husband's position in the society was linked to deinfibulation (Johansen 2017b, 536; Nour et al. 2006, 58; Safari 2013, 156).

Fear of not being able to get married was a strong barrier to not undergo premarital deinfibulation as the marriage for women is highly valued inside the communities even though she would be living in Western countries (Nour et al. 2006, 58; Safari 2013, 156). One study had an example of a 38-year-old woman origin of Sudanese living in Norway. She came from an educated family, had negative attitude towards infibulation, and did not find religious support for the practice. Despite these, she was strongly reluctant to undergo deinfibulation although she suffered daily pain and discomfort from infibulation. She did not see premarital deinfibulation as an option because it would ruin her virginity. (Johansen 2017b, 536.) Another study showed an example where deinfibulation was performed on a single woman living in UK. At the time she was about to get married, her partner left her as soon as he found she was deinfibulated, expressing to her that she is not normal. (Catania et al. 2007, 1674.)

Husband's agreement to perform deinfibulation is important according to one study. Safari's (2013, 157) study findings indicate that married women who had discussed the deinfibulation with their husbands and had their agreement had fewer problems later. Sometimes husbands preferred the woman to stay infibulated. The same study described a situation where the woman wanted to undergo the deinfibulation but her husband did not let her. She did not want to risk her marriage so she did not do the operation. Eventually, she did not undergo deinfibulation even during childbirth because she had all four children by caesarean section. Another woman described that her second marriage failed partly because her husband wanted to her to be infibulated. However, not all husbands preferred women to stay infibulated or they might have fears unrelated to the infibulation itself. In one case the husband was resistant

against the operation only because he was scared for the woman thinking that the operation is dangerous. Another case the husband wanted the woman to undergo deinfibulation after finding out that the sex was impossible with so narrow orifice. (Safari 2013, 157.)

6.2.4 The value of women virginity and virtue

Infibulation is closely intertwined with the value of women virginity and virtue. Premarital deinfibulation is believed to ruin virginity and undermine women's virtue by enabling, facilitating and even encouraging woman to practice promiscuity. Even though women would be aware of the possibility of surgical deinfibulation, and they would accept it in the cases of several health complications caused by FGM, in the actual cases, many choose not to undergo as the premarital virginity and virtue would be compromised. (Johansen 2017b, 535-536.) Sometimes these beliefs are so strong that it prevents women to seek adequate treatment. Like in the case of 35-year-old women participant originated from Somalia in the study conducted in Norway. In the study, she described that she resisted the procedure for years because she feared that it would make her crazy about men and wanting to have sex with anyone she meets. (Johansen 2017b, 536.)

Johansen's (2017a, 10) study suggest that sexual concerns, such as ideas surrounding women's virginity and virtue should be taken into account in a significantly higher degree than it is now when it comes medical counselling and preventive interventions. Some people are also starting to question these values. One 28-year-old Somali originated participant decided to undergo deinfibulation at the age of 15 due several health problems caused by FGM. A contributing factor to undergo deinfibulation most likely was that she had been living with Norwegian foster parents since early-teenage. Although she was afraid of the surgery beforehand, she described that the procedure not only relieved her physical problems but also helped her to get a sense of regaining control over her body. She was not worried of failing her virginity test since she did not intend to marry a Somali man, although she eventually did. (Johansen 2017b, 537-538.)

6.2.5 The value of men virility and pleasure

Many times, women or men do not recognize medical deinfibulation as an option. There is a strong belief that penile deinfibulation is the only normal and acceptable way of opening the stitched area. Penile infibulation is highly emphasized because it proves men's virility and masculinity. Many women also tend to accept that the pain of the penile deinfibulation as a self-evident part of it, although it could be avoided by surgical deinfibulation. (Johansen 2017a, 6-7; Moxey & Jones 2016, 5.) In Johansen's (2017a, 6) study participants described that the penile deinfibulation took a month of repeated penile pressure, resulting in open wounds and extreme pain before the vaginal penetration succeed. Even during this process, medical

deinfibulation wasn't considered as an option because women considered that "it wasn't so bad". (Johansen 2017a, 6.) In another story, a Sudanese man revealed that he failed to penetrate his wife. He did not want to use force and cause pain on her fearing that the extreme pain would traumatize her, and thereby fearing that it would ruin their marriage. His wife refused to undergo surgical deinfibulation. After six years of marriage, never having sexual intercourse, they ended up divorcing. He said that this experience ruined his life, and he was exposed to mock and shame by his ex-wife's family for failing his test of manhood. (Johanson 2017a, 7.)

The ideal of penile deinfibulation is in some cases discussed as a thing of the past or that it is only custom in origin countries but this belief is still valued by many, especially among Sudanese men according to a study conducted in Norway (Johansen 2017a). In one case, Sudanese woman argued for a long time with her husband before he agreed that she could undergo deinfibulation but before that she had to promise to keep the operation a secret. In some cases, the surgical deinfibulation is seen to be shameful because it means that the husband has failed to create a penile opening, and therefore failed to prove his manhood. On contrary, according to the same study, Somali men and women don't emphasize penile infibulation in their personal lives so much. Instead, some Somali women criticize this value. Also, in two cases, the husbands were relieved when they found out that their wife had less extensive infibulation, thereby reducing deinfibulation difficulties. (Johansen 2017a, 7.)

Men's sexual satisfaction was also seen as important and linked to infibulation. In the cases where women refused deinfibulation or only wished for partial opening, the main reason was that the tight vaginal opening was seen prerequisite for male sexual pleasure. Women feared that if they can't fulfil their husbands' sexual needs, they would seek sexual fulfilment elsewhere and the marriage would be endangered. Both men and women shared similar views regarding vaginal tightness to ensure sexual pleasure for a man. A worry of being unable to provide male sexual pleasure was often the reason to request re-infibulation after delivery. (Johansen 2017a, 7-8.)

6.3 Advantages and disadvantages of deinfibulation

Only six of our studies described the deinfibulation procedure itself. Deinfibulation was performed either under local anaesthesia with the help of scissors either in the outpatient clinic (Albert et al. 2015, 432; Bikoo, Davies, Richens & Creighton 2006, 404) or during labour usually when the baby's head is crowning (Albert et al. 2015, 432; Nour et al. 2006, 56; Rouzi, Aljhadali, Amarin & Abduljabbar 2001, 108; Rouzi et al. 2012, 100). One study evaluated the use of carbon dioxide laser surgery in deinfibulation (Penna et al. 2002, 1550). Deinfibulation can be partial or total (Catania et al. 2007, 1672; Abdulcadir et al. 2015, 175). Persons who performed the

deinfibulation were mentioned to be the specialist FGM midwifes (Albert et al. 2015, 432) or residents or senior residents (Rouzi et al. 2012, 100). In most studies, the performer of deinfibulation was not identified.

Deinfibulation has been described as a simple procedure (Abdulcadir et al. 2014, 298; Rouzi et al. 2001, 950). Studies indicate that there rarely occur any intraoperative complications like bleeding or pain during or after procedure (Penna et al. 2002, 1552-155; Rouzi et al. 2001, 950; Rouzi et al. 2012, 101). Some patients might have shown moderate pain during the local anesthetic but it was not a reason to stop the treatment. Patients whom where deinfibulated in the outpatient clinic, were able to leave the health care facility soon after the procedure. (Penna et al. 2002, 1552-1553). Most patients recovered more easily than they expected, and they resumed their daily lives soon after the intervention (Nour et al. 2006, 57; Rouzi et al. 2012, 101). Berg et al (2017a) concluded that most women did not have any complications. In 1-3 months follow up, recovery and healing were satisfactory and anatomical results were good (Berg at al. 2017a, 280).

Some complications occurred also but they were mostly minor. Two studies described cases where the deinfibulated women had spontaneous reattachment of the scar edges a few days after delivery (Abdulcadir et al. 2015, 175; Berg et al. 2017a, 280). Following this, treatment practices were developed to avoid future spontaneous reattachment. (Abdulcadir et al 2015, 175.) Some patient had postoperative discomfort of varying degrees in the deinfibulated areas. The discomfort lasted 3 to 5 days. Patients who were treated for cyst in addition of deinfibulation, reported a minor blood loss during the first 5 days after the deinfibulation. (Penna et al. 2002, 1553.) Another study reported that four (7,7%) patients who were deinfibulated intrapartum a wound breakdown was found, which was treated conservatively (Wuest et al. 2009, 1206). In a large systematic literature review including 7291 women, postoperative complications occurred among 12,4% women. Complications were minor complications such as wound and urinary tract infections. (Berg at al. 2017a, 280.) Another study reported that 12% of the participants complained of occasional dyspareunia after deinfibulation (Nour et al. 2006, 57).

6.3.1 Impact of deinfibulation on obstetric outcomes

The main motivation to seek deinfibulation for majority of the women is to facilitate childbirth. Women described childbirth to be easier after the deinfibulation procedure (Berg et al. 2017a, 284-285; Moxey & Jones 2016, 4; Rouzi et al. 2001, 951). Studies show how high standard of obstetric care (e.g. deinfibulation and follow-up of the pregnancy) can minimize risks associated to FGM (Abdulcadir et al. 2014, 297; Rouzi et al. 2001, 951).

There is controversial evidence about the impact of FGM reversal on caesarean delivery. Raouf, Ball, Hughes, Holder and Papaioannou (2011, 143) stated in their study that multiparous women with reversal of FGM had lower risk of caesarean delivery compared with both the general multiparous population of the hospital and with non-reversed multiparous. Non-reversed multiparous had significantly higher risk for caesarean section when compared to the general multiparous population in the hospital. In other words, deinfibulation performed on multiparous women decreases their risk of caesarean section caused by FGM III. For primiparous women there was no significant difference between women with reversed FGM and women with non-reversed FGM. Same study also reported on their research that 182 of 230 deinfibulated women (79.1%) had normal vaginal deliveries and 3 women (1%) had instrumental deliveries. (Raouf et al. 2011, 142-143). Two other studies found a significant difference in caesarean section in a favour that women with deinfibulation had lower risk of caesarean section (Berg et al. 2017b, 281; Okusanya et al. 2017, 15). Other studies did not find either significant difference on caesarean section rate in comparing women with deinfibulation to women who delivered without deinfibulation (Esu et al. 2017, 27) or there was no caesarean section performed due FGM (Abdulcadir et al. 2015, 175; Bikoo et al. 2006, 404; Rouzi et al. 2001, 951; Rouzi et al. 2012, 100-101; Wuest et al. 2009, 1206). Findings indicate that deinfibulation does not prolong second stage of labour (the period of time when the cervix is fully dilated until the baby is born) (Okusanya et al. 2017, 15). Studies also found that there is no significant difference in the duration of labour between women who had undergone deinfibulation during the labour and those who were not deinfibulated (Okusanya et al. 2017, 15; Rouzi et al. 2012, 101) or women without FGM (Okusanya et al. 2017, 15; Rouzi et al. 2001, 951; Wuest et al. 2009, 1206).

Two studies found the episiotomy rate to be higher among women with FGM (Abdulcadir et al. 2015, 176; Bikoo et al. 2006, 404). One study suspected the rate to be high due that the episiotomies were sometimes performed on women with FGM although it was not always recommended beforehand (Abdulcadir at al. 2015, 176). Other studies did not find significant difference in episiotomy risk between women who have undergone deinfibulation and those who were not deinfibulated (Berg et al. 2017b, 281; Esu et al. 27; Okusanya et al. 2017, 15; Rouzi et al. 2012, 101) or women without FGM (Okusanya et al. 2017, 15; Rouzi et al. 2001, 950; Wuest et al. 2009, 1206). Women with FGM have more emergency and third-degree tears but less first and second-degree tears compared to women without FGM. (Wuest et al. 2009, 1206.) Studies suggest that women who underwent deinfibulation had lower risk in all degree perineal tears compared to women with no deinfibulation. Findings also indicate that women who underwent deinfibulation have similar risks in perineal tears compared with women without FGM which underlines the important potential benefits of deinfibulation suggesting that deinfibulation can remove the obstetrics risks caused by FGM (Abdulcadir et al. 2015, 176; Berg et al. 2017b, 281; Okusanya et al. 2017, 18).

One study found that women who were deinfibulated had a significantly lower risk of postpartum haemorrhage compared to women with FGM III without deinfibulation (Okusanya et al. 2017, 15). Other studies did not find significant difference in postpartum haemorrhage with deinfibulation versus no deinfibulation (Berg et al. 2017b, 281; Esu et al. 2017, 27; Rouzi et al. 2012, 101) or deinfibulation versus no FGM (Okusanya et al. 2017, 15; Rouzi et al. 2001, 950; Wuest et al. 2009, 1206). There was no significant difference in maternal hospital stay between deinfibulated women and women without deinfibulation (Okysanya et al. 2017, Rouzi et al. 2001, 950). Neither there was no significant difference in Apgar scores with women who underwent deinfibulation versus women without deinfibulation (Okusanya et al. 2017, 15; Raouf et al. 2011, 142; Rouzi et al. 2012, 101) or deinfibulated women versus women with no FGM (Rouzi et al. 2001, 950; Okusanya et al. 2017, 152; Wuest et al. 2009, 1206).

6.3.2 Impact of deinfibulation on sexuality

Deinfibulation facilitated the sexual problems associated with FGM, and women reported a positive result on sexual function after deinfibulation procedure (Berg et al. 2017b, 281; Catania et al 2007; 1672; Johanson 2017a, 7; Johanson 2017b, 281; Nour et al. 2006, 57-59). One observational study reported the physical and sexual outcomes after deinfibulation in mainly Somali women living in United States. Participants were all satisfied with the results and 94% felt that they could endorse others to go through it also. They felt that post-operative course was less painful and traumatic than they expected. Women also felt that the deinfibulation had corrected their physical problems. Patients were also happy with their sexual life and new appearance of their genitalia. 100% of women felt that their sexual intercourse had improved significantly after the procedure. (Nour et al. 2006, 57-59). Another study described that several participants in the study had been unable to have vaginal intercourse for months or even for years after their marriage before they sought help. One surgeon reported of the case where he treated a woman who was seeking help for infertility after twelve years of marriage. Clinician confirmed that the couple had never had vaginal intercourse, and she was still fully infibulated. (Johansen 2017a, 7.) Some women report improvements in physiological functions after deinfibulation such as less painful intercourse and menstrual cramps, decreased urinary and vaginal infections and improvement in flow of urination and menstrual flux (Catania et al. 2007, 1672; Berg et al. 2017a, 284; Nour et al. 2006, 59). Another study reported how 14 out of 15 women could have an orgasm with penetrative vaginal intercourse a few months after the procedure (Catania et al. 2007, 1672).

6.3.3 Satisfaction of deinfibulation

Studies reported high satisfaction after the surgery (Berg et al. 2017a, 984; Nour et al. 2006, 59-60; Moxey & Jones 2016, 4; Wuest et al. 2009, 1206). Both women and men were pleased

about their decision about going through deinfibulation. Husbands were supportive after they had the possibility to be involved in the process. The process included being informed about female genital mutilation, learning what tissue is removed, what health consequences the practice involved and the subsequent risks and benefits of deinfibulation. (Nour et al. 2006, 59-60.) In one study women where asked about their satisfaction after deinfibulation. 53% told that they were satisfied, 23% were more or less satisfied and 12% were not satisfied. 12% did not want to answer the question. Those who were not satisfied had some complications after the procedure, they had requested postpartum re-infibulation or the dissatisfaction was unrelated to deinfibulation. (Wuest et al. 2009, 1206.)

Although deinfibulation often improves women's health and eases the complications caused by FGM, it will change women body image and physiology. Women need supportive care as they might have doubts before the procedure and the new appearance can be disconcerting and unsettling to the women. Women described that they were used to how it looked before and it looked normal before. The new appearance did not many times make women feel comfortable with it. The new appearance was described as "funny", "like an empty place", "it doesn't look good" or "it looked better when closed". (Abdulcadir et al. 2014, 300; Safari 2013, 157; Smith & Stein 2017, 44.) One woman described her new appearance "healthy" and that she did not mind that it was open as long she felt OK with it and her husband was happy (Safari 2013, 157).

6.4 Ideal time to undergo deinfibulation

The ideal timing of deinfibulation is controversial and significant gaps in the evidence exist (Abdulcadir et al. 2014, 300; Albert et al. 2015, 437; Esu et al. 2017, 26). Abdulcadir et al. (2014) surveyed in their study evidence gaps in the care of women with female genital mutilation. As a conclusion, they concluded that there is an urgent need for evidence on the ideal timing of deinfibulation. They also highlighted that it is not currently known how the timing of deinfibulation affect the acceptability of the procedure or health outcomes. Because of these gaps, the available recommendations on the ideal timing of deinfibulation differ among countries. The existing recommendations are currently based solely on expert opinion. (Adbulcadir et al 2014, 300.) No studies concerning specifically the ideal timing of deinfibulation outside of pregnancy was found. One study including 25 women, mostly non-pregnant, recommended that deinfibulation should be offered to all infibulated woman (Penna et al. 2002, 1550). However, few studies which had studied timing of deinfibulation during pregnancy were found.

6.4.1 Deinfibulation during pregnancy

Four studies surveyed the ideal timing of deinfibulation during pregnancy (Albert et al. 2015; Berg et al. 2017a; Esu et al. 2017; Paliwal et al. 2013). Studies explored if the timing of deinfibulation has an effect on obstetric outcomes. Deinfibulation performed during pregnancy (antenatal) and during the labour (intrapartum) were compared. Studies did not identify which gestational weeks the deinfibulation was performed during the pregnancy nor the time of deinfibulation during labour. Three of the studies did not find any significant differences in the following obstetric outcomes: duration of labour, perineal trauma, Apgar score or caesarean section rate (Berg et al. 2017a, 282; Esu et al. 2017, 27; Paliwal et al. 2013, 285). No difference in haemorrhage was found in two studies (Berg et al. 2017a, 282; Esu et al. 2017, 27).

One study indicated that regardless of timing of deinfibulation, all women in their study had higher risk for caesarean section, instrumental births, episiotomy, and perineal tears when comparing to local and national rates. The rate of perineal tears was found unexceptionally high. Additionally, in women whose deinfibulation was delayed until the time of delivery had a significantly higher risk of episiotomy and a prolonged hospital stay compared to women who underwent deinfibulation prior to labour. (Albert et al. 2015, 437.) Another study also indicated similarly that women whose deinfibulation was performed during labour were significantly more likely to have an episiotomy than women who were deinfibulated before labour. They also observed that women who had deinfibulation performed during pregnancy had lower blood loss in the labour versus women who were deinfibulated during labour. (Paliwal et al. 2013, 285-286.) A large systematic review studied the effectiveness of surgical interventions for women with FGM. Their meta-analyses did not find any statistically significant differences between antenatal deinfibulation versus intrapartum deinfibulation although they found favourable effect of deinfibulation relative to none with respect to caesarean delivery and perineal trauma (Berg et al. 2017a, 284).

Studies discussed that despite the lack of evidence, the ideal timing of deinfibulation should be considered. The deinfibulation performed before labour should be offered to the women with type III as it might produce preferable obstetric outcomes. (Albert et al 2015, 437; Berg et al. 2017a, 284; Esu et al. 2017, 28; Paliwal et al. 2013, 287.) One study argued that deinfibulation performed during pregnancy could allow the woman to heal before delivery and give her time to get used to her new appearance. Also, among women who have low utilization of maternity care, deinfibulation performed before labour would most likely result in better obstetric and neonatal outcomes. It also highlighted the need to evaluate women's preferences of the timing of deinfibulation. (Esu et al. 2017, 27-28.)

6.4.2 Women's preferences of the timing of deinfibulation

Women's own wishes for the timing of deinfibulation differ. When studying pregnant women, studies indicate that the majority of the women preferred to undergo deinfibulation during the labour rather than the antenatal period although the procedure would have been recommended to performed before labour (Bikoo et al. 2006, 404; Momoh et al. 2001, 190; Moxey & Jones 2016, 4-5; Wuest et al. 2009, 1205). In one study consisting 122 participants, eight women decided to have antenatal deinfibulation, 52 requested deinfibulation during labour, 42 women were preferred to undergo deinfibulation during labour only if it was considered necessary by the health care professionals and 20 women were unable to articulate their wishes (Wuest et al. 2009, 1205). In the study consisting mostly non-pregnant women, 25 women requested deinfibulation. Of them, fourteen had never been sexually active, and seven of them were pregnant between 10 and 37 weeks of gestation and they were seeking deinfibulation to facilitate labour. (Penna et al. 2002, 1552.) In another study, sixteen women were recommended for deinfibulation prior to labour. Ten women agreed to the procedure and it was done during the same clinic visit. The mean gestation week of deinfibulation was 27 weeks. Six patients decided to wait until labour. (Bikoo et al. 2006, 404.) One study conducted in UK consisted in 39 pregnant women. Only three women chose to undergo deinfibulation before delivery and the rest preferred to be deinfibulated during the labour. (Momoh et al. 2001, 190.) In a study consisting of 129 women, women were given the option to choose either partial or total deinfibulation. Most of the women (n=59) had been deinfibulated during a previous labour. Intrapartum deinfibulation was performed in 25 women. 13 women preferred partial deinfibulation and only four patients had a total deinfibulation. Three women who underwent caesarean delivery requested and were deinfibulated during the same operating time. (Abdulcadir et al. 2015, 175.) In a larger study including 253 women, nine were deinfibulated antenatally, 18 opted the deinfibulation during delivery, 18 had no deinfibulation at all and 208 had undergone the procedure in their previous pregnancy. (Paliwal et al. 2014, 285.)

The most common reason to choose deinfibulation during labour rather than deinfibulation during pregnancy were that women were reluctant to undergo invasive procedure twice (Momoh et al. 2001, 190; Moxey & Jones 2016, 4-5). In one study women stated that the deinfibulation would have been performed during labour in their country of origin (Somalia) so that was their preference also. It was also discussed that the planning of the ideal deinfibulation time depends if the women in need of deinfibulation are identified in the early pregnancy. The sensitive nature of topic, as well as the language barrier, and the lack of knowledge within the health care professionals may lead to that women do not know to seek deinfibulation during pregnancy. It is notable that many infibulated women are asylum seekers which may lead to

that they have late antenatal booking or that their care during pregnancy is fragmented. (Bikoo et al. 2006, 404.)

7 Discussion

The evidence indicates that there are multiple factors which facilitate or act as a barrier to use of deinfibulation. Women are seeking deinfibulation for various reasons, pregnancy and health problems related to FGM being the most prevalent. Despite of the women need or will to undergo deinfibulation, there are multiple factors which act as barriers. Themes such as health care professionals' lack of knowledge and inexperience to perform deinfibulation, culturally sensitive care, challenges in communication and cultural factors emerged from the evidence. Health care professionals seem to have significant gaps in knowledge, management and experience regarding FGM and deinfibulation. There are also communication challenges between the health care professional and the patient as well as between different health care facilities leading to a lack of clarity in the care and treatment of women with FGM. These factors both prevent women with FGM to receive adequate care as well as it weakens the women's will to seek care especially in the Western health care settings.

Well-designed and evidence-based guidelines are essential tools when promoting quality health care (Garner, Hill & Schünemann 2015, V). Identifying barriers and facilitators of the use of deinfibulation helps health care professionals when creating practical guidelines concerning the care of women with FGM. Evidence reveals the urgent need of education and training among health care professionals. For example, Royal College of Obstetrician & Gynaecologists (2015, 3) recommends that all obstetricians, gynaecologists and midwives should receive mandatory training on FGM and its's management, including the technique of deinfibulation. In Finland, FGM is a part of curriculum of midwives and obstetricians but implementing this training varies. Nonetheless, FGM is not part of some other health care professional's curriculum e.g. public health nurses, who are in the key role of identifying the girls and women who have undergone FGM at the school health care and maternity clinics.

There are several cultural values which underlie deeply the practice of infibulation, and thereby causes resistance against surgical deinfibulation. Parents' fear of that the girl will remain unmarried if she does not undergo FGM, and the value of women's premarital virginity are strong motivators to carry on the practice of FGM (World Health Organization 2017a). Evidence indicate that these fears and values are also dominant reasons why the girl or woman may not consider a premarital surgical deinfibulation as an option although it would be medically advised. Even if the girl or woman would adapt new cultural values by living in the Western country and would not personally emphasize these traditional values, fear of parents' disapproval or fear of being excluded from her own community may keep her from seeking help.

Deinfibulation is strongly related to sexuality which makes the issue taboo in many cultures and deinfibulation is not often discussed not even with closest relatives or friends. Increasing the awareness of deinfibulation among the communities affected by FGM is a way tackling this taboo.

Earlier study has shown that FGM plays a significant role in marital dissatisfaction (Koolaee et al. 2012, 115). Cultural values also guide the male behaviour and thinking. Some cultures may highly emphasize the value the penile deinfibulation which may put a heavy pressure on men from outside of the relationship or sometimes even from the wife. Failure in performing the penile deinfibulation or the repeated pain caused by it for the women may lead to sexual and marital dissatisfaction or even divorce in some cases. Evidence suggest that these factors are not currently considered enough when caring women with FGM nor in the prevention of FGM practice. Varol, Turkmani, Black, Hall and Dawson (2015) concluded in their systematic review about the men's role in abandonment of FGM, that the social obligation, and the lack of communication between men and women are the key issues which men recognized to be as barriers to abandonment of FGM. Education was the strongest influence for men's support for the abandonment of FGM. (Varol et al. 2015, 1.) It is likely that education, advocacy by men and co-operation between women and men in community programs can be a crucial contributor in abandonment of this practice as well as could be in accepting the surgical deinfibulation.

Advantages and disadvantages of deinfibulation are an under-researched issue. There is not much evidence of the consequences. No studies which would have compared different deinfibulation techniques were found. The most commonly used technique was the procedure implemented with scissors. One study described the operation performed with carbon dioxide laser. Laser surgery in gynaecology has been used over 30 years with good results and patient safety records (DeLeon & Baggish 2008). However, it is not so commonly used in deinfibulation. In the light of a current evidence, the deinfibulation procedure is described as a simple procedure which has little intraoperative or postoperative complications. If complications occur, they are mostly minor such as discomfort, wound infections or labial reattachments.

Previous studies provide a clear evidence that FGM entails troubles on women's physical health throughout her life (Berg et al. 2014, 4-9). According to the general assumption, deinfibulation can reverse some of the adverse health outcomes caused by FGM. Nevertheless, existing studies reveals a very little evidence on the impact of deinfibulation on physical problems. The evidence suggests that deinfibulation can decrease problems such as painful menstruation, urinary tract infection and vaginal infections. WHO strongly recommends the use of deinfibulation for preventing and treating urologic problems such as urinary tract infections and urinary retention in girls and women living with type III FGM, although they have not

reported any direct evidence of the effectiveness of the deinfibulation (World Health Organization 2016, 7).

Relevant additional evidence was found on the impact of the deinfibulation on obstetric outcomes. The existing evidence indicates that deinfibulation decreases some of the adverse obstetric risks related to type III FGM such as caesarean section, perineal tears and post-partum haemorrhage. It is noteworthy that deinfibulation was not linked to any negative influence in any adverse obstetric outcome. Our findings were consistent with the WHO recommendation of the deinfibulation. WHO states that deinfibulation is recommended for women with type FGM III for preventing obstetrics complications (strong recommendation; very low-quality evidence) (World Health Organization 2016, 7).

WHO's (2006, 6) large prospective study conducted in six African countries indicates that FGM is associated with adverse obstetric and neonatal outcomes with increased risks of caesarean section, postpartum haemorrhage, episiotomy, resuscitation of the infant and extended maternal hospital stay when compared to women without FGM. It is noteworthy that although the included studies were conducted in seven different countries, the most of them were carried out in Western countries. The prevalence of FGM and deinfibulation is not so common in Western countries, and the quality of healthcare facilities is higher compared to for example many parts of Africa where FGM is more prevalent and health care facilities are of lower quality. If the woman has access to high-quality maternity services, it alone seem to be an independent factor reducing the obstetric risks caused by FGM. This indicates that adverse obstetric outcomes related to FGM are likely less severe in Western countries than in developing country settings despite of the deinfibulation.

Little evidence was found on how deinfibulation effects on sexuality. Sexual consequences of FGM are an under-researched and overlooked issue (Berg et al. 2010, 6). Similarly, the impact of deinfibulation on women's sexuality is under-researched. Studies which measured the sexual function before and/or after deinfibulation were made with varied methods which complicates the conclusion making. Findings suggest that women were overall satisfied with the result of deinfibulation and they felt that their sexual life improved after deinfibulation. Women also reported that the intercourse had improved significantly as it was less painful. Deinfibulation corrected women's infertility in the cases where the infertility was the result of obstructed intercourse. Husbands seemed to be satisfied with the deinfibulation but there was little evidence concerning the husbands´ opinions. Contradictory, some women had difficulties adapting the new body imagine caused by deinfibulation. Re-infibulation was requested in some cases.

WHO (2016, 24) states (best practice statement 3) that girls and women who will receive or have received any surgical intervention to correct health problems caused by FGM should get psychological support. By getting the adequate psychosocial and emotional support, girls and women would be more prepared for adapting the new body image after deinfibulation as well as it would help them deal with the initial trauma caused by FGM which may come up during the time of deinfibulation or during the labour. Study findings highlighted the fact that there is a gap in knowledge related to the women's experiences of deinfibulation. Despite the lack of evidence, by opening the closed vaginal opening, deinfibulation facilitates sexual intercourse and restores normal physiological functions (Berg et al. 2017b, 284).

The ideal timing to undergo deinfibulation remains contradictory in the light of research results. Few studies explored the timing of deinfibulation during pregnancy by comparing the deinfibulation performed before labour and during labour. Regardless of the timing of deinfibulation, there was no significant differences when measuring obstetric outcomes but some trends were seen in favour of deinfibulation performed before labour. Deinfibulation performed before labour seemed to result in more favourable obstetrics outcomes, especially among women who do not have access or will to use maternity services. It was also discussed that if deinfibulation is performed before labour, it would give the women time to heal before labour as well as it would give them time to get used to their new body image before it changes again after delivery.

There are gaps in the evidence and available recommendations differ from country to country or are lacking totally. This study's data search did not identify any specific recommendations although there are some recommendations. For example, the Royal College of Obstetrician & Gynaecologists (2015, 16) recommends that for women with type III FGM, deinfibulation should be offered antenatally in the second trimester of pregnancy, typically around 20 weeks of gestation. WHO (2016) recommends that deinfibulation should be performed either before labour or during labour to facilitate childbirth in women with type III FGM depending on the context. Due to their guidelines, both deinfibulation performed before or during pregnancy are comparable in terms of obstetric outcomes. Decision about the ideal timing of deinfibulation should be based on the contextual factors: the woman's own wishes, her access to health care facilities, the place of the delivery and the health care provider's skills. (World Health Organization 2015, 19.) No studies or recommendations concerning the ideal timing of deinfibulation outside of pregnancy was found.

Although the findings indicate that the deinfibulation performed before labour (antenatal) may be preferable, women were not willing to choose antenatal deinfibulation. The majority of women chose to undergo deinfibulation during labour as they did not want to go through two invasive procedures. Studies did not identify whether the women got any guidance so it is not

known whether their choice was informed choice. WHO recommends that women who are candidates for deinfibulation should get adequate pre-operative guidance (World Health Organization 2016, 7). If women would get appropriate information of the benefits of deinfibulation before labour, it is possible that they would choose otherwise. Additionally, if the woman places high importance on the postoperative aesthetic result, deinfibulation is preferable to be performed before labour (World Health Organization 2016, 19). The current evidence reveals that there are significant gaps in knowledge of understanding women's views of the acceptability of the deinfibulation, preferred time to undergo deinfibulation as well as the women feelings about the outcomes of deinfibulation.

7.1 Strengths and Limitations

The strength of the current study is that it presents comprehensive view of the existing evidence on deinfibulation related practises globally. Deinfibulation related practices have not been surveyed this broadly before, at least not in Finland. There is one other literature review related to deinfibulation made in Finland by bachelor students but the focus of the study was more narrow, the study only included seven studies, and the study purpose was to produce instruction material on deinfibulation (Laukkanen & Sorsa 2013). Also, that review was conducted in 2013. More than half of our data is published after that, which makes our study more up-to-date.

The strength of this study is that it had broad inclusion criteria, all study designs were accepted which enabled finding a comprehensive amount of existing studies. The inclusion criteria were limited to studies published in English or Finnish which leads to publication bias. The publication bias may have excluded some evidence which could have enhanced this review. Apart from language limitations, only "grey literature" such as textbooks, narrative literature reviews, case reports and pro-gradu theses were excluded, in order to conduct a high-quality literature review.

Like all reviewers, we are limited to what is reported. The strength of this study is, that the quality of the included studies was assessed carefully with appropriate assessment tools. Overall, the quality of the included studies was moderate or high. In some studies, the data extraction was challenging because of the poor reporting and interpretation of the evidences. The majority of our studies are observational and qualitative studies, which is typical in the view of the topic of this review. Some of these study evidence was assessed to be low-quality and biased, which means that the evidence must be interpreted with caution, and the generalizability of the evidence is not strong. Nevertheless, the strength of this integrative literature review is that it merges data from different types of study designs. Although the strength of the observational or qualitative studies is not in their generalizability, the strength

of those study designs lies in their ability to produce in-depth understanding. Observation and interviews can reach people in their real-life situation, and it can provide detailed information about human behaviour, emotions and personality characteristics which are essential when considering the topic of this review. Furthermore, although many gaps in the evidence were identified, the available evidence were able answer to the research questions in many ways.

7.2 Ethical consideration

This study was a theoretical study so no ethical approval typical for empirical studies was needed. However, to conduct an ethical literature review, it means that the authors have certain responsibilities. This means that the review must be conducted and reported in a transparent way. The potential conflicts of interest and funding sources must be declared, the data extraction must be done accurately, redundant publications in the study should be avoided, and the review should not contain plagiarized material (Wager & Wiffen 2011, 130-134).

In this study, the authors have no conflicts of interest. No funding sources were used for this study. The progress of this study is descripted accurately, and in a transparent way, so that the reader can easily follow it through. One of the author has experience in systematic literature review from earlier studies but the experience is almost from a decade ago. This can have both a positive and negative impact on the search and the review process. Nonetheless, to avoid negative impact, the literature search was performed with the help of a professional librarian in order to execute an up-to-date and high-quality search. Authors attempted to make the assessment of the studies as unbiased as possible by assessing the studies both individually and together. In the cases of disagreement, compromises were made on basis of discussion. It is still possible, that different authors may evaluate and interpret the findings differently. References used in this study were attempted to mark accurately and no plagiarized material was used. Reporting of this study was aimed to be done in a way that it would not victimize any of the involved parties while addressing the main issues.

7.3 Authors' contribution and acknowledgement

The authors worked together to perform the integrative review process. The first author was mainly responsible for preparing the theoretical background while the second author was responsible for the finishing. Both authors were equally responsible for the data search, data evaluation and data interpretation. Both authors participated in writing the report and discussion, although the first author was more responsible. It is notable that the reporting and discussion was based on continuous mutual reasoning. The study was performed as part of the authors' Master studies in Laurea University of Applied Sciences.

7.4 Implications for practice and future research

Literature reviews are an important part of the medical or nursing evidence as it can be an efficient mean to advance clinical practice toward evidence-based care. This study's objective was to seek evidence of deinfibulation related issues facilitating the guideline creation process for professionals working with women who have undergone FGM. Improving the health outcomes of women living with FGM, the guideline development process needs to be embedded in the health system at all levels. These study findings can facilitate the guideline creation process as it points out many issues which should be considered during the process. Before this study was officially published, some actions were already made. Instructions for midwifes on how to perform deinfibulation during labour was published in HUS intranet in February 2018 with the help of the first the author (Appendix 6). Both authors participated in a FGM network meeting organized by The Finnish League for Human Rights (Ihmisoikeusliitto) on March 2018. The FGM network purpose is to increase the awareness of FGM and improve the health outcomes of women living with FGM as well as preventing the practice of FGM. The network includes professionals from different areas e.g. Ministry of Social Affairs and Health, National Institute of Health and Welfare, The Finnish League for Human Rights, Finnish Immigration Service and National Police Board. The first author kept a lecture about "the deinfibulation from the midwife's point of view" at the meeting, where some of these study findings were also discussed (Appendix 7). Both authors will continue the work of increasing the awareness of FGM and deinfibulation.

Our findings indicate that there are several needs for future research. The current evidence is lacking well designed larger observational studies of the effectiveness of deinfibulation related practices. The existing evidence is also lacking "gold standard" trials, in other words randomized controlled trials evaluating interventions such as e.g. deinfibulation to improve health or obstetric outcomes of women with FGM. Such studies would be the most desirable study designs as it is seen to minimise the selection of bias. On the other hand, randomized controlled trials can be ethically doubtful and difficult to execute considering the issue. In study setting where the deinfibulation would not be offered for all infibulated women can be highly unethical as the deinfibulation is strongly recommended in the light of current evidence. There is also a need to study women's motivation and experiences on deinfibulation as well as there is need to study the viewpoints of the partners. It is also noteworthy that our study did not identify any studies conducted in Finland related to deinfibulation. In the case we want to design healthcare services that can respond to the needs for women living with FGM, it would be essential to get domestic evidence of deinfibulation related issues regarding the skills, training and confidence of health care professionals as well as the viewpoints of women living

with FGM in Finland. It would be also important to study the timing of deinfibulation outside of pregnancy as there are no studies regarding that currently.

8 Conclusion

The current integrative review was conducted to seek evidence on deinfibulation related practices facilitating the guideline creation process in Finland for professionals working with women who have undergone FGM. Evidence of the factors that facilitate or act as a barrier to use of deinfibulation, advantages and disadvantages of deinfibulation, and the best timing of deinfibulation were reviewed. This study included 22 studies of a variety of designs. Attitudes, knowledge, experience, communication and cultural factors were identified as barriers and facilitators in the use of deinfibulation. Deinfibulation is a minor procedure which can reverse many adverse health outcomes caused by FGM such as physiological, sexual and obstetric outcomes but this study also identified many gaps in the current evidence. The ideal timing of deinfibulation outside of pregnancy has not been studied, during the pregnancy the antenatal and intrapartum deinfibulation are comparable in the terms of obstetric outcomes although some trends in favour of antenatal deinfibulation were seen. Women's preferences of the timing of deinfibulation differs although most women seem to prefer undergoing deinfibulation during labour.

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Figures

Tables

Appendices

Appendix 1: Timetable

STAGES	TIMETABLE
Planning stage	
• Choosing the subject and method and presenting the topic to our tutor teacher.	• March 2017
• Thesis plan	• October 2017
Implementation stage	
• Literature search and collecting data.	• December 2017
• Data evaluation.	• January – February 2018
• Data analysis and writing synthesis	• February 2018
Final stage	
• Presenting the results.	• March 2018
• Publication	• April 2018

Appendix 2: Characteristics of included studies

REFERENCE	COUNTRY	PURPOSE AND AIM OF THE STUDY	DESIGN AND STUDY SAMPLE	DATA AND METHODS	RESULTS	QUALITY ASSESSMENT
Abdulcadir et al. 2015. Obstetric care of women with female genital mutilation attending a specialized clinic in a tertiary center.	Switzerland	To study the obstetric outcomes of women attending a specialized clinic for women with female genital mutilation (FGM).	A retrospective observational study Participants 129 women. Majority of participant were originated from Eritrea and Somalia. Other countries were Guinea, Ethiopia, Sudan, Burkina Faso, Egypt, Yemen, Ivory Coast, Djibouti, Liberia, Senegal, Cameroun, Gambia, Mali and Sierra Leone.	The medical charts of women with FGM who consecutively attended a specialized clinic between 2010 and 2012 were reviewed retrospectively. Study focused on women attending for obstetric reasons. The outcome measures were type of delivery, reason for caesarean section or assisted delivery, blood loss, episiotomy, perineal tear, duration of the second stage of labour, postpartum complications, neonates weight and Apgar score. The outcomes were compared between women with type III FGM who underwent deinfibulation, and patient with type I and III FGM.	129 women attended to the clinic, 84 prenatally. Obstetric outcomes were similar to average outcomes for women without FGM presenting at the same department and in Switzerland generally. 20 women had caesarean delivery. 18 women had assisted delivery, among these, eight had experienced obstructed labour. No statistically significant differences were found for the outcomes measures when women with FGM type III were compared to FGM type I and II. **Conclusions:** Routine obstetric follow-up combined with specialized care for women with FGM, including deinfibulation, can avoid inappropriate obstetric practices and reduce obstetric complications known to be associated with FGM.	40/44 (91%) (A)
Abdulcadir et al. 2014. Research gaps in the care of women with	Switzerland	Researchers reviewed awareness gaps in the clinical care of women	Systematic review Obstetric outcomes	Researchers searched the PubMed database for articles concerning the care of women with FGM in any country, published	Researchers pointed out an urgent need for well-designed research to create evidence-based guidelines and to improve	31/46 (67%) (C)

female genital mutilation: an analysis.		with FGM. They wanted to focus on obstetric outcomes, surgical interventions like deinfibulation and clitoral reconstruction, and the abilities and education of healthcare professionals involved in the prevention and administration of FGM. They recognized main concerns of the research so they could increase the evidence concerning creation of guidelines for the best multidisciplinary care, communication and prevention. They also wished to increase health-promotion measures for women with FGM.	and postpartum perineal re-education = 24 references Deinfibulation outside of pregnancy labour = 9 references Clitoral reconstruction = 10 references Role of healthcare professional = 12 references	in any language, starting from 1986 to January 2014. A mixture of medical subject headings (MeSH), text, and keywords were used. Researchers wanted to include reviews, retrospective and prospective cohort studies which provide quantitative and qualitative data, audits, case reports, comments, guidelines, and experts´ opinions on their study. After the search, evidence was categorized thematically. Those areas were selected and arranged on the basis of the absence of clinical guidelines, controversy in management, and the potential to significantly affect the health of women living with FGM. All researchers reviewed and summarized paper.	the health care of women and girls with FGM. Future studies should emphasis on addressing existing research gaps like as obstetric outcome, difficulties, sexuality, and therapeutic surgeries. Diversity of women should be taken into consideration when implementing future studies. Variables like culture, origin, experience and different type of cutting should be taken into consideration. Researchers should include countries of origin and countries of migration to their study. Also, women who have undergone FGM should be involved designing the research so they could make researchers to understand what research they want and need. Training of caregivers characterises another large field of work and study. Evidence will help to create guidelines for the best multidisciplinary care, interaction, prevention, and improvement of health promotion measures.	

Albert et al. 2015. Does the timing of defibulation for women with type 3 female genital mutilation affect labour outcomes?	UK	To determine whether timing of deinfibulation effects obstetric outcomes for women with type III female genital mutilation (FGM)	A retrospective observational study 94 women with type 3 FGM who gave birth from 2008-2012. Majority of the women were originated from Somalia.	Outcome described in maternity notes of women with deinfibulation performed prior to labour (n=62) compared with not deinfibulated before labour (n=32). Secondary analysis was then performed excluding women who had caesarean sections.	Women who were not deinfibulated before labour had a significantly greater risk of episiotomy (RR 1.67, P<0.05) and prolonged hospital stay of >2days (RR 1.33, P<0.05). They also had non-significant risk of a postpartum haemorrhage (RR 1.15, P=0.58); prolonged second stage (RR 1.77, P=0-16); and required vaginal packing in theatre (RR 2.6, P=0.17). There was no difference on Apgar scores, and both emergency section and instrumental birth rates were higher than national average level. **Conclusions:** Type III FGM is related to morbidity in childbirth. Risk of morbidity is higher when deinfibulation is deferred until labour.	41/44 (91%) (A)
Berg et al. 2017a. Reasons for and experiences with surgical interventions for female genital mutilation/cutting (FGM/C): A systematic review.	Norway	To perform a systematic review of empirical quantitative and qualitative research on interventions for women with FGM/C-related complications.	Systematic review Research included 71 studies including 7291 women were eligible for inclusion. Almost all women in the included	Study conducted systematic searches in 16 databases to gain references from different disciplines. All study designs were accepted containing of girls and women who had been exposed to FGM/C and that examined a reparative intervention for a FGM/C-related concern. The titles,	Researchers found out FGM/C is attracting more attention especially in Western countries. Despite large number of researches, methodologically valid studies of reparative interventions for FGM/C-related problems are sparse. Researchers identified three types of reparative interventions	45/46 (98%) (C)

			studies were originated from Africa. Most frequent countries were Somalia, Sudan, Burkina Faso, and Nigeria.	abstracts, and full texts of retrieved records for relevance were screened. Methodologic quality of the included studies was assessed and extracted and synthesized the study data.	which are deinfibulation, cyst removal and repair, clitoral-labial reconstruction. Out of those three, deinfibulation is the simplest and most accessible procedure, whereas accessibility for reconstruction is limited. There are some data on women´s motivation for surgery and those were categorized on functional complaints, aesthetic aspirations, sexual aspirations, and identity recovery. Study pointed out how there is little evidence whether women are satisfied with the surgery. Also, women´s experiences appear mixed. Further research on this are of analysis is needed.	
Berg et al. 2017b. The effectiveness of surgical interventions for women with FGM/C: A systematic review.	Norway	Systematic review of empirical quantitative research on the outcomes of interventions for women with FGM/C-related complications.	Systematic review Research included 62 studies (5829 women), which investigated the effect of deinfibulation, excision of cysts, and clitoral reconstruction. All women	A search specialist searched 16 electronic databases. Selection was performed independently by two researchers. Researchers accepted quantitative studies that examined the outcome of an intervention for an FGM/C-related concern. Researchers extracted data into a pre-designed form, calculated effect estimates, and performed meta-analyses.	Meta-analyses of deinfibulation versus no deinfibulation showed a significantly lower risk of caesarean section (relative risk, RR: 0.33; 95% confidence interval, 95% CI: 0.25-0.45) and perineal tears with deinfibulation: second-degree tear (RR: 0.44, 95% CI: 0.24-0.79), third-degree tear (RR: 0.21, 95% CI: 0.05-0.94), fourth-degree tear (RR: 0.06, 95% CI: 0.01-0.41). The meta-analyses	48/48 (100%) (C)

			where from countries where FGM is commonly practiced.		detected no significant differences in obstetric outcomes of antenatal versus intrapartum deinfibulation. Except for one study, none of the studies on the excision of cysts indicated any complications, and the results were deemed favourable. Reconstructive surgery resulted in a visible clitoris in about 77% of women. Most women self-reported improvements in their sexual life, but up to 22% experienced a worsening in sexuality-related outcomes after reconstruction. **Conclusions:** Women with FGM/C who seek therapeutic surgery should be informed about the scarcity of evidence for benefits and the potential harms of the available procedures.	
Bikoo et al. 2006 Female genital mutilation: A growing challenge for midwives in the UK.	UK	To define the need for antenatal deinfibulation and subsequent obstetric outcomes of women with FGM.	A prospective cohort study. Study sample was 26 women. Majority (20/26) of women were originated from Somalia.	All women attending the AWC for assessment and deinfibulation before delivery during study period were enrolled in the study. Clinical assessment was performed and medical records were reviewed.	67% required deinfibulation prior to delivery, 79% sustained either an episiotomy or tear. Significant number (38%) declined antenatal deinfibulation, favouring to wait until labour. Caesarean section and instrumental deliveries were equivalent to the hospital average. All	27/44 (61%) (A)

					women with or without deinfibulation, had remarkably high levels of perinea trauma.	
Catania et al. 2007. Pleasure and orgasm in women with female genital mutilation/cutting (FGM/C).	Italy	To describe and analyse the results of four investigations on sexual functioning in different groups of mutilated women.	A qualitative study Study sample was 137 adult women affected by different types of FGM/C; 58 young FGM/C ladies living in the West; 57 infibulated women; 15 infibulated women after the operation of deinfibulation.	Semi structured interviews and the Female Sexual Function Index (FSFI) were used as an instrument of the study.	The group of 137 women, affected by different types of FGM/C, reported orgasm in almost 86%, always 69.23%; 58 mutilated young women reported orgasm in 91.43%, always 8.57%; after deinfibulation 14 out of 15 infibulated women reported orgasm; the group of 57 infibulated women investigated with the FSFI questionnaire showed meaningful differences between group of study and an equivalent group of control in desire, arousal, orgasm, and satisfaction with mean scores higher in the group of mutilated women. There were no noteworthy differences between the two groups in lubrication and pain. **Conclusions:** Embryology, anatomy, and physiology of female erectile organs are neglected in specialist textbooks. In infibulated women, some erectile structures fundamental for orgasm have not been removed. Cultural influence and social acceptance can change the	16/20 (80%) (B)

					sensation of pleasure. Every woman has right to have sexual health and feel sexual pleasure for full psychophysical well-being. In accordance with other research, the present study reports that women who have undergone FGM/C can also have the possibility of reaching an orgasm. Therefore, FGM/C women with sexual malfunctions can and must be cured; they should have an appropriate sexual therapy.	
Esu et al. 2017. Antepartum or intrapartum deinfibulation for childbirth in women with type III genital mutilation: A systematic review and meta-analysis.	Nigeria	To perform a systematic review of the effects of antepartum or intrapartum deinfibulation on labour outcomes in women with type III FGM.	Systematic review Two studies were included. In both studies participants were predominantly from Africa.	The following major databases were searched: Cochrane Central Register for Controlled Trials (CENTRAL), MEDLINE, Scopus, Web of Science, and ClinicalTrials.gov, from inception until August 2015 and with no language restrictions. Researchers include studies of pregnant women or girls with type III FGM who were deinfibulated before or during a pregnancy.	There is no evidence of a noteworthy difference between antepartum and intrapartum deinfibulation for obstetric outcomes. Outcomes are for example duration of labour, perineal lacerations, episiotomies, postpartum bleeding, and caesarean sections. There was no statistically difference on outcomes between women living with type III FGM and those who have undergone deinfibulation. On contrary, trends show an advantage for deinfibulation. All studies were underpowered to notice statistical differences.	43/48 (90%) (C)

					Conclusions: Larger studies are essential to develop full certainty on these conclusions.	
Johansen. 2017a. Virility, pleasure and female genital mutilation/cutting. A qualitative study of perceptions and experiences of medicalized defibulation among Somali and Sudanese migrants in Norway.	Norway	To explore the perceptions and experiences of surgical deinfibulation among migrants in Norway and consider whether surgical deinfibulation is a familiar medicalization of a traditional procedure or instead confronts the cultural underpinnings of infibulation.	A qualitative study Participants with 36 women and men of Somali and Sudanese origin and with 30 service providers.	Data derived from in-depth interviews, as well as participant observations in various settings from 2014-15. Data was thematically analysed.	The study outcomes indicate that, despite negative thoughts towards infibulation, its cultural meaning in relation to virility and sexual pleasure establishes a barrier to the approval of medicalized deinfibulation. **Conclusions:** As sexual concerns regarding virility and male sexual pleasure establish a barrier to the acceptance of medicalized deinfibulation, health care providers need to report sexual concerns when discussing treatment for complications in infibulated women. Additionally, campaigns and counselling against this tradition also need to tackle these sexual interests.	20/20 (100%) (B)
Johansen. 2017b. Undoing female genital cutting: Perceptions and experiences of infibulation, deinfibulation and virginity	Norway	To explore experiences and observations of premarital deinfibulation. It explores whether Somali and Sudanese men and women	A qualitative study Participants 36 women and men of Somali and Sudanese origin.	Study analyses data from in-depth interviews as well as participant observation conducted in various settings during 2014 -2015.	Findings reports that although all of the informants presented negative attitudes towards infibulation, cultural meanings connected with virginity and virtue constitute a significant obstacle to the	20/20 (100%) (B)

among Somali and Sudanese migrants in Norway.		understand deinfibulation as simply medical issue or whether their use of the services is also affected by the cultural meaning of infibulation.			endorsement of premarital deinfibulation.	
Momoh et al. 2001. Female genital mutilation: Analysis of the first months of a Southeast London specialist clinic.	UK	To analyse the sources and reasons for referral of women who have gone through female genital mutilation to a recently established specified clinic, and to define the consequences of the genital mutilation process.	An observational retrospective descriptive case series. Study population of hundred and eight (n=108) women. All but one participant were originated from Sub-Saharan Africa.	Main outcome measures were sources and reasons for referral to the specified clinic; characteristics of the women attending the specified clinic; acute and chronic complications of the FGM procedure and attitude towards FGM.	Complete case records were available for 108 women. Acute and chronic complications were each present in 86% of women with type III FGM. Most women (82%) were referred by their midwife because they were pregnant, of whom 48% were primigravid. Eighteen non-pregnant women attended the clinic to requesting either deinfibulation or asking for an advice. Almost 6% were seriously considering having their daughter go through genital mutilation outside the UK. Less than 10% of the women refused to continue the tradition of female genital mutilation. **Conclusions:** Especially doctors and midwives should ask specifically about female genital mutilation when taking care of women from high	28/42 (66%) (A)

					risk countries, and suggest the services of specialised clinics for FGM	
Moxey & Jones. 2016. A qualitative study exploring how Somali women exposed female genital mutilation experience and perceive antenatal and intrapartum care in England.	UK	To explore how Somali women exposed to female genital mutilation experience and perceive antenatal and intrapartum care in England.	A qualitative study Participants were convenience and snowball sample of ten (n=10) Somali women resident in Birmingham, who had accessed antenatal care services in England within past five years.	Study was guided by using face-to-face semi-structured interviews. Interviews were recorded, transcribed and analysed by using a thematic method. An interpreter was used in three (n=3) cases.	Three main themes were interpreted: (1) Experiences of female genital mutilation during life, pregnancy and childbirth: FGM had a meaningful physical and psychological effect, inducing decisions to undergo deinfibulation or caesarean section. Women postponed deinfibulation until labour to avoid undertaking multiple operations if an episiotomy was predicted. Experience of care from midwives: Awareness of FGM from midwives directed to open communication and stronger relationships with women, causing more positive experiences. Adaptation to English life: Good language skills and social support networks empowered women to access these services, while unfavourable social factors (e.g. incapability to drive) hindered. **Conclusions:** FGM influences Somali women's experiences of antenatal and intrapartum care. Open communication facilitates more positive	20/20 (100%) (B)

					experiences. Strategies to endorse deinfibulation to non-pregnant women should be considered. Women with poor social factors may require additional support to expand access to English antenatal care services.	
Nour et al. 2006. Deinfibulation to treat female genital cutting: Effect on symptoms and sexual function.	USA	To study the physical and sexual outcomes after deinfibulation and evaluate both patient and husband satisfaction	An observational study Forty (n=40) consecutive women with a history of type III female genital cutting who underwent deinfibulation between 1995 and 2003. 95% of the participants were originated from Somalia.	Medical records were reviewed. Data collected included demographics, indications for the practice, closure type, intraoperative and postoperative complications. Telephone surveys were conducted between 6 months and 2 years post procedure to assess the long-term health and sexual satisfaction outcomes.	Of 40 women identified as having undergone deinfibulation, 95% were Somali, 65% were married, and 73% were between the ages of 19 and 30. Primary indications for deinfibulation were being pregnant (30%), dysmenorrhea (30%), apareunia (20%), and dyspareunia (15%). Secondary indications were apareunia (20%), difficulty urinating (12.5%), and dyspareunia (10%). Sixty-five percent had a subcuticular repair. Forty-eight percent had an intact clitoris buried beneath the scar. No one had intraoperative or postoperative complications. 94% of the patients stated they would recommend deinfibulation to others. 100% of patients and their husbands were pleased with the results, felt their appearance had	33/42 (79%) (A)

					improved, and were sexually fulfilled. **Conclusions:** Deinfibulation is recommended for all infibulated women who suffer long-term complications.	
Okusanya et al. 2017. Deinfibulation for preventing or treating complications in women living with type III female genital mutilation: A systematic review and meta-analysis.	Nigeria	To assess the influence of deinfibulation on gynaecologic or obstetric outcomes by comparing women who were deinfibulated with women with type III FGM or women without FGM.	Systematic review Four case-control studies were included.	Major databases including CENTRAL, MEDLINE, and Scopus were searched until August 2015. SELECTION CRITERIA: Nonrandomized studies which compared obstetric outcomes of women with deinfibulation, type III FGM (not deinfibulated during labour), and no FGM, were included. Quality of evidence was defined following the GRADE methodology. Summary measures were estimated using odds ratios at 95% confidence intervals	No randomized controlled trials were found. The quality of evidence was very low. Compared with women with type III FGM at delivery, deinfibulated women had a notable reduction in the risk of having a caesarean delivery or postpartum bleeding. Compared with women without FGM, deinfibulated women had a comparable risk of episiotomy, caesarean delivery, vaginal lacerations, postpartum bleeding and blood loss at vaginal delivery. The length of second stage of labour, mean maternal hospital stay, and Apgar scores less than 7 were also relative. **Conclusions:** Low-quality evidence proposes that deinfibulation improves labour outcomes for women with type III FGM.	42/46 (91%) (C)

Paliwal et al. 2013. Management of type III female genital mutilation in Birmingham, UK: A retrospective audit.	UK	To audit clinical management of women with type III female genital mutilation (FGM) according to local guidelines. Secondary objectives were to describe the population that uses the service and compare obstetric outcomes of intrapartum deinfibulation and antenatal deinfibulation.	A retrospective audit 253 women with type III FGM who gave birth at a hospital midwifery-led FGM specialist service in Birmingham between January 2008 and December 2009. Majority of the women were originated from Somalia (92,9%). Other countries were Eritrea, Sudan, Yemen, Sierra Leone, Nigeria and Kenya.	Study was conducted as retrospective case analysis using patient records. Proportion of women managed according to locally agreed criteria for the management of FGM; obstetric outcomes including perineal tears, episiotomy rates, estimated blood loss, infant Apgar scores and indications for caesarean section.	91 (36%) women booked into antenatal care after 16 weeks of gestation. Only 26 (10,3%) were managed fully according to guidelines. The poorest performance area with was child protections, where the presence of normal genitalia was documented in only 52 (38,8%) of medical notes following birth of a female infant. Most of the women (214, 84,6%) had been deinfibulated in a previous pregnancy. Of the 39 infibulated women only 9 (23,1%) were deinfibulated antenatally, the rest chose intrapartum deinfibulation. Women who had intrapartum deinfibulation had a higher average haemorrhage and more perineal tears than those who were deinfibulated antenatally, although this was not statistically significant. **Conclusions:** Further research is needed to confirm or refuse the adverse findings among those women whose deinfibulation was delayed.	42/42 (100%) (A)
Penna et al. 2002. Type III female genital	Italy	To examine clinical implication of	An observational study	Deinfibulation was performed in an outpatient setting with	The carbon dioxide laser procedure restored a complete vulvar opening in	25/42 (59%)

mutilation: Clinical implications and treatment by carbo dioxide laser surgery.		type III female genital mutilation and to evaluate the use of carbon dioxide laser surgery to restore vulvar opening and to treat associated epithelial inclusion cysts.	Twenty-five (n=25) infibulated patients who underwent carbon dioxide treatment. 23 women were originated from Somalia, two from Ethiopia.	local anaesthesia. A colposcopy-guided laser beam was used to create an incision along the fusion midline of the labia majora. In case of vulvar epidermal inclusion cyst, the capsule was opened and emptied of sebaceous contents; the inner surface of the cyst was vaporized completely.	all 25 patients. Seven of the women (28%) were pregnant, between 10 and 37 weeks of gestation. Vulvar examination revealed five cases of epidermal inclusion cysts. No intraoperative or postoperative complication occurred. Pregnant women who underwent deinfibulation had spontaneous vaginal delivery and no evidence of perineal trauma. **Conclusions:** Deinfibulation treatment should be offered to all infibulated patients. The procedure is particularly appropriate during pregnancy to prevent childbirth complications. Laser carbon dioxide has been proved to be a suitable technique for the treatment of female genital mutilation when inclusion cysts are associated with it.	(A)
Raouf et al. 2011. Obstetric and neonatal outcomes for women with reversed and non-reversed type III female	UK	To record and compare obstetric and neonatal complication rates in women with reversed and non-reversed type III female genital	A retrospective observational study The records of first 250 women with type III FGM that were	Study compared the caesarean delivery rates and neonatal outcomes of primiparous and multiparous women who had or had not undergone reversal of FGM III. Data were collected for their first delivery and were cross-checked with	Of the 250 women, 230 (92%) underwent deinfibulation. Of these, 50 (21,7%) were primiparous (caesarean delivery rate 17/50; 34%) and 180 (78,3%) were multiparous (caesarean section rate 28/180; 15,6%). Of the 20 women	40/44 (91%) (A)

genital mutilation.		mutilation (FGM)	seen in the clinic since the clinic was establishmen t in 2002 were identified. 96% of women were originated from Somalia. Rest were from Ethiopia, Gambia, Egypt and Kuwait.	hospital notes. Outcome measures were the mode of delivery, rates of episiotomy, and perineal tears, as well as estimated blood loss and Apgar scores.	who did not undergo deinfibulation, 7 (35%) were primiparous (caesarean section rate 5/7 (71,4%) and 13 (65%) multiparous (caesarean section rate 7/13 (53,8%). The caesarean section rates for primipara and multipara were 32,9% and 25%, respectively. Multiparous women with deinfibulation had a lower possibility of caesarean section compared with the general hospital multiparous population and multipara who did not undergo deinfibulation. There were no significant association between Apgar score or haemorrhage at vaginal delivery and FGM reversal. **Conclusions:** Deinfibulation significantly reduced the increased risk of caesarean delivery seen with multipara with FGM III.	
Rouzi et al. 2012. Defibulation during vaginal delivery for women with type III female genital mutilation.	Saudi-Arabia	To assess the routine practice of deinfibulation during vaginal delivery for women who have undergone female genital mutilation	A case-control study 388 women underwent deinfibulatio n during vaginal delivery (77,3% were	Study was conducted on women from Sudan, Somalia, Ethiopia, Egypt, and Yemen who delivered at King Abdulaziz University Hospital from 1.1. 2000 to 30.11. 2011. Deinfibulated women were identified, and their records were examined.	No caesarean section was performed because of FGM. No spontaneous rupture of the infibulation scar occurred. There were no statistically significant differences between women who had deinfibulation versus those who did not or between	36/44 (82%) (A)

			registered during pregnancy, 22,7% were unregistered) , women who did not have deinfibulatio n were chosen as a control group (n=388). Women were originated from Sudan, Somalia, Egypt, Eritrea and Yemen.	Control group consisted of women from same nationality who delivered without deinfibulation on the same day or next day. Data collected included demographics, mode of delivery, blood loss, intraoperative and postoperative complications, and labour outcomes.	infibulated registered and unregistered women in the duration of labour, episiotomy rates, haemorrhage, Apgar score, or fetal birth weight. **Conclusions:** Deinfibulation during labour is a valid management option. Labour attendants should be trained to perform deinfibulation.	
Rouzi et al. 2001. The use of intrapartum defibulation in women with female genital mutilation.	Saudi-Arabia	To assess the use of intrapartum deinfibulation for women who have had female genital mutilation.	A retrospective case analysis Two hundred and thirty-three (n=233) Sudanese and ninety-two (n=92) Somali women who were delivered at the hospital between January 1996 and December 1999.	The outcome of labour of women with female genital mutilation who needed intrapartum deinfibulation were compared with the outcome of labour of women without female genital mutilation who did not need intrapartum deinfibulation.	158 (48.6%) women had infibulation and needed intrapartum deinfibulation to deliver vaginally, 116 women (35.7%) did not have infibulation and gave birth vaginally without deinfibulation, and 51 (15.7%) women had caesarean section. There were no statistically significant differences, between women who underwent intrapartum deinfibulation versus women who did not, in the duration of labour, rates of episiotomy and perineal tears, APGAR scores, haemorrhage and maternal stay in hospital. The	30/42 (71%) (A)

					surgical technique of intrapartum deinfibulation was easy and no intraoperative complications occurred. **Conclusions:** Intrapartum deinfibulation is simple and safe. Sensitivity to the cultural issues involved need to be considered.	
Safari 2013. A qualitative study of women's lived experience after deinfibulation in the UK.	UK	To explore women's experiences of deinfibulation and its aftermath.	A qualitative study Study included nine women participants of Somali and Eritrean origin who had Female Genital Mutilation (FGM) type III previously and underwent deinfibulation between January 2008 and September 2009.	Study was conducted by using semi-structured interviews with data collection via audio-recording and field notes. The audio-recorded interviews were transcribed verbatim and analysed using Interpretive Phenomenological Analysis (IPA) method for qualitative data analysis.	Findings identified some key themes: the cultural meaning and social acceptability of deinfibulation; the consequences of deinfibulation within marital relationships; feelings about the appearance of genitalia post deinfibulation and thoughts on re-infibulation. **Conclusions:** marital factors and stability of the relationship influence the experience of deinfibulation. Husbands' involvement in decision making reported to have less problems afterwards. Women with pre-marital may face more difficulties in terms of social acceptability within their community.	20/20 (100%) (B)
Smith & Stein 2017. Surgical or medical	UK	To provide information on the factors that	A qualitative evidence synthesis	All studies were conducted in high-income countries: France (n=1),	Findings indicates that women may not be willing to be deinfibulated for	15/16 (67%)

interventions female genital mutilation.		facilitate or act as a barrier to use deinfibulation, and the context and conditions that are necessary for implementing the procedure, including healthcare providers' knowledge and experience, the service delivery environment, as well as broader health system contexts.	Six studies were included in the qualitative synthesis.	Norway (n=2), UK (n=1) and Sweden (n=2). Qualitative evidence synthesis was produced from the studies	following reasons: concerns about the physical appearance after the procedure, concern about social unacceptability of the procedure and the fear that provider don't have adequate skills or experience to perform deinfibulation. Findings also indicates that there is a lack of knowledge among health workers regarding deinfibulation as well as poor communication between healthcare provider and infibulated women.	(B)
Wuest et al. 2009 Effects of female genital mutilation on birth outcomes in Switzerland.	Switzerland	To determine the desires and wishes of pregnant patients vis-à-vis their external genital anatomy after female genital mutilation (FGM) in the context of antenatal care and delivery in a teaching hospital setting in Switzerland. Majority of women were originated from	A retrospective case-control study One hundred and twenty-two (n=122) patients after FGM who consent to participate the study and who delivered in the Department of Obstetrics and	Data for patients' wishes concerning their FGM management, their satisfaction with the postpartum outcome and intrapartum and postpartum maternal and fetal data. Control group consisted of pregnant women without FGM who delivered at the same time and who were matched for maternal age. Main outcome measures were patients' satisfaction after delivery and deinfibulation after FGM, maternal and fetal delivery data and	6% of patients wished to be deinfibulated antenatally, 43% requested a deinfibulation during labour, 34% desired a deinfibulation during labour only if considered necessary by the medical staff and 17% were unable to express their wishes. There were no significant differences for FGM patients and controls in duration of delivery, fetal outcome or post-partum haemorrhage. FGM patients had significantly more often emergency caesarean deliveries and third-degree vaginal tears,	42/44 (95%) (A)

		Somalia (n=42), Sudan (n=33) and Ethiopia (n=27). Others were from Tanzania, Kenya, Egypt and from Far East,	Gynaecology in the University Hospital of Berne and 110 controls.	postpartum outcome measures.	and significantly less first-degree and second-degree tears. **Conclusions:** An interdisciplinary approach may support optimal antenatal and intrapartum management and also the prevention of FGM in newborn daughters.	

Appendix 3: Quality assessment of observational studies applied from STROBE Statement (A)

REFERENCE	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	
Abdulcadir et al. 2015	••	••	••	••	••	••	••	••	o	••	••	••	••	••	••	••	••	••	••	••	••	o	40/44 (91%)
Albert et al. 2015	••	••	••	••	•	••	••	••	o	••	••	••	••	••	••	••	••	••	••	••	••	••	41/44 (93%)
Bikoo et al. 2006	••	••	••	••	••	••	••	•	o	•	•	o	••	••	•	•	o	••	o	•	•	o	27/44 (61%)
Momoh et al. 2001	••	••	••	•	••	••	X	••	o	•	•	o	••	••	••	••	•	••	o	••	o	o	28/42 (66%)
Nour at al. 2006	••	••	••	••	••	••	X	••	o	••	•	•	••	••	••	••	o	•	••	••	••	o	33/42 (79%)
Paliwal et al. 2013	••	••	••	••	••	••	X	••	••	••	••	••	••	••	••	••	••	••	••	••	••	••	42/42 (100%)
Penna et al. 2002	••	••	••	••	••	••	X	•	o	•	o	•	••	••	•	•	•	•	o	•	•	o	25/42 (59%)
Raouf et al. 2011	••	••	••	••	••	••	••	••	o	••	••	••	••	••	••	••	••	••	••	••	••	o	40/44 (91%)
Rouzi et al. 2001	••	••	••	•	••	••	X	•	o	•	••	••	••	•	••	••	•	••	•	•	•	o	30/42 (71%)
Rouzi et al. 2012	••	••	••	••	••	••	••	••	o	••	•	••	••	••	••	••	••	••	o	••	•	o	36/44 (82%)
Wuest et al. 2009	••	••	••	••	••	••	••	••	o	••	••	••	••	••	••	••	••	••	••	••	••	••	42/44 (95%)

1. Study title and abstract is defined
2. Background of the study in explained
3. Objectives are stated
4. Study design is presented
5. Study settings are described
6. Participants eligibility criteria are presented
7. Variables are defined
8. Data sources/measurement are described
9. Bias are defined
10. Study size is explained
11. Quantitative variables are explained
12. Statistical methods are described
13. Number of the participants is reported and explained
14. Descriptive data is presented
15. Outcome data is reported
16. Main results are reported
17. Other analyses are reported
18. Key results are summarised
19. Study limitations are discussed
20. Interpretation is presented
21. Generalisability is discussed
22. Funding is reported

•• Satisfies assessment criterion
• Partly satisfies assessment criterion
o Hardly or not at all satisfies assessment criterion
X Assessment criteria do not appl

Appendix 4: Quality assessment of qualitative studies applied from CASP (B)

REFERENCE	1	2	3	4	5	6	7	8	9	10	
Catania et al. 2007	••	••	••	•	••	•	•	••	••	•	16/20 (80%)
Johansen 2017a	••	••	••	••	••	••	••	••	••	••	20/20 (100%)
Johansen 2017b	••	••	••	••	••	••	••	••	••	••	20/20 (100%)
Moxey & Jones 2015	••	••	••	••	••	••	••	••	••	••	20/20 (100%)
Safari 2011	••	••	••	••	••	••	••	••	••	••	20/20 (100%)
Smith & Stein 2017	••	••	••	o	•	x	•	•	•	••	12/18 (67%)

1. Aims of the research are clearly stated
2. Qualitative methodology is appropriate
3. The research design is appropriately addressed to the aims of the research
4. Recruitment strategy is appropriate to the aims of the research
5. The data is collected in a way that it addresses the research issue
6. The relationship between researcher and participants are adequately considered
7. Ethical issues have been taken into consideration
8. The data analysis is sufficiently rigorous
9. The findings are clearly stated
10. The value of the research is discussed

•• Satisfies assessment criterion
• Partly satisfies assessment criterion
o Hardly of not all satisfies assessment criterion
x Assessment criteria do not apply

Appendix 5: Quality assessment of systematic reviews applied from PRISMA 2009 Checklist (C)

REFERENCE	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	
Abdulcadir et al. 2014	•	••	•	••	••	••	•	•	•	o	••	••	•	x	••	••	o	•	••	•	••	o	•	••	31/46 (67%)
Berg et al. 2017a	••	••	••	••	••	••	••	••	••	••	••	••	•	x	••	••	••	••	••	••	••	••	••	••	45/46 (98%)
Berg et al. 2017b	••	••	••	••	••	••	••	••	••	••	••	••	••	••	••	••	••	••	••	••	••	••	••	••	48/48 (100%)
Esu et al. 2017	••	••	••	••	••	•	••	••	••	••	••	••	••	•	••	••	••	••	••	•	••	••	••	o	43/48 (90%)
Okusanya et al. 2017	••	••	••	••	••	•	••	••	••	••	••	••	•	x	••	••	••	••	••	••	••	••	••	o	42/46 (91%)

1. Study title and abstract is defined
2. Background of the study is explained
3. Objectives are stated
4. Selecion criteria is presented
5. Information sources are presented
6. Full electronic search strategy for at least one database is explained
7. Process for selecting studies is explained
8. Method of data extractions from reports are described
9. All variables for which data were sought are listed and defined
10. Methods used for assessing bias of individual studies are described
11. Principal summary measures are stated
12. The methods of handling data and combining results of studies are described
13. Any assessment of risk of bias that may affect the cumulative evidence is specified
14. Additional analyses of methods are described
15. Study selection is explained
16. Characteristics of each study are presented
17. Risk of bias of each study is presented
18. Results of individual studies are presented
19. Synthesis of results is presented
20. Risk of bias across studies is presented
21. Summary of main findings are included
22. Limitations at study and outcome level are discussed
23. A general interpretation of the results in the context of other evidence is provided
24. Funding is reported

•• Satisfies assessment criterion
• Partly satisfies assessment criterion
o Hardly or not at all satisfies assessment criterion
X Assessment criteria do not apply

Appendix 6: Instructions for midwifes how to perform deinfibulation during labour by Heidi Kytöaho

TYTTÖJEN JA NAISTEN YMPÄRILEIKKAUKSEN AVAUS SYNNYTYKSEN YHTEYDESSÄ

- Ohje kätilölle

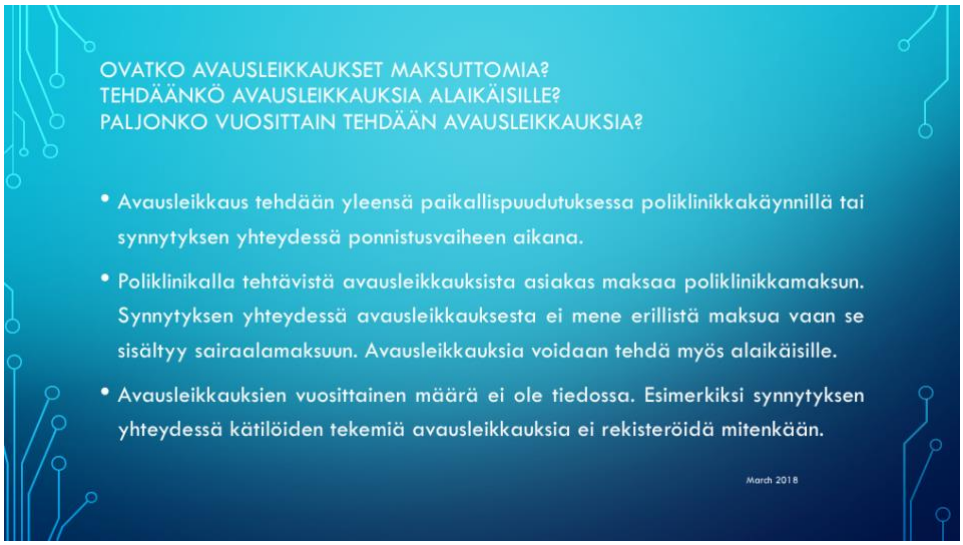
Tyttöjen ja naisten ympärileikkaus tyyppi III (infibulaatio) tulee avata synnytyksen yhteydessä. Tyttöjen ja naisten ympärileikkaus, erityisesti tyyppi III, aiheuttaa naiselle monenlaisia fyysisiä, psyykkisiä ja seksuaalisia ongelmia ja voi komplisoida myös raskauden ja synnytyksen. Jos ympärileikattua naista ei ole aiemmin avattu, tulee ympärileikkauksen avaus (defibulaatio) suorittaa ponnistusvaiheen yhteydessä. Ensisijaisesti ympärileikkaus avataan, episiotomia tehdään vain tarvittaessa. Synnyttäjän, ja mielellään myös puolison (synnyttäjän luvalla) kanssa, tulee asiasta keskustella synnytyksen aikana ja kertoa perustelut toimenpiteen suorittamiselle. Ota huomioon, että synnyttäjällä saattaa olla traumoja ympärileikkaukseen liittyen, jotka saattavat aktivoitua synnytyksen aikana. Synnyttäjällä saattaa olla myös väärinkäsityksiä/tiedonpuutetta liittyen ympärileikkaukseen/anatomiaan. Pyri oikaisemaan näitä.

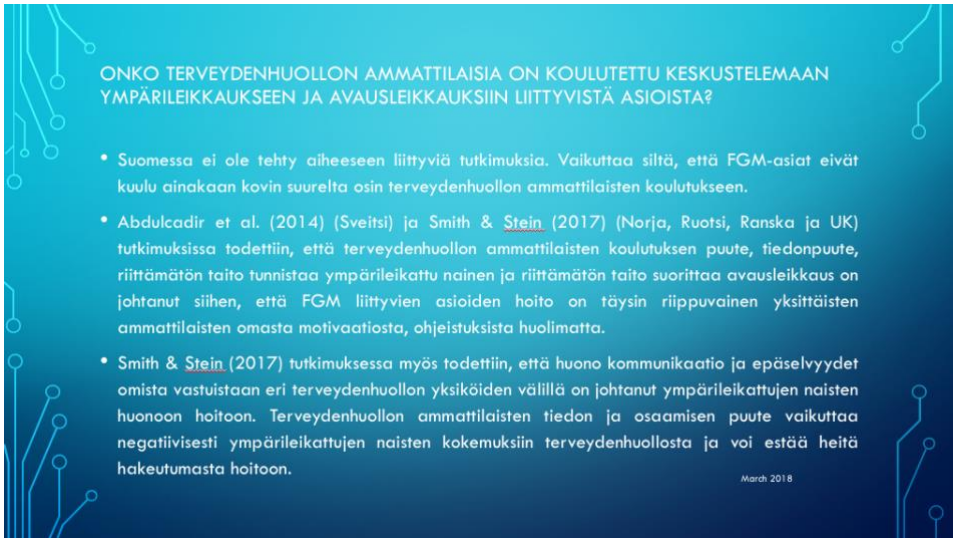
Avausleikkaus (defibulaatio) toimenpiteenä ponnistusvaiheen yhteydessä:

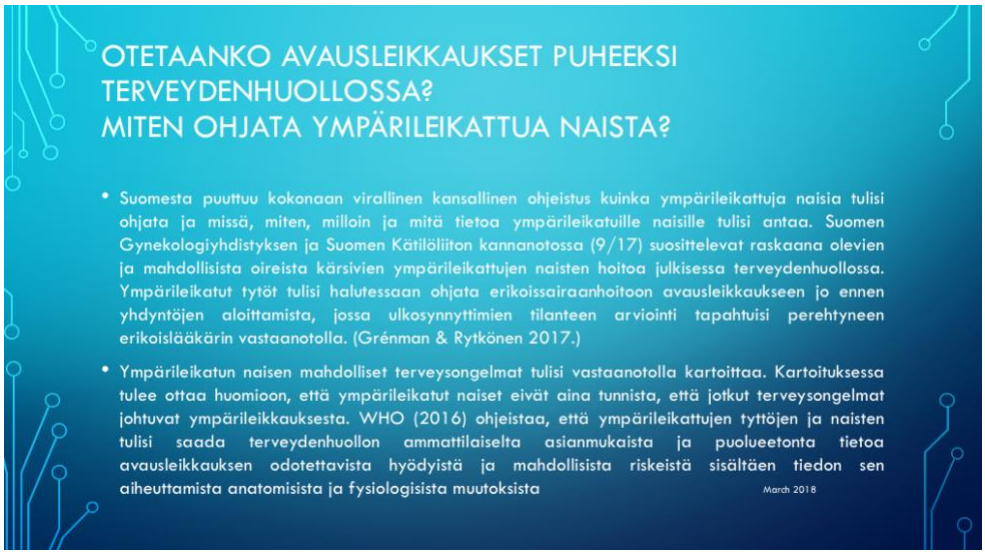
1. Palpoi arven alle mahdollisesti jäänyt klitoris.
2. Vie infibulaatioarven alle sormi tai instrumentti ja nosta arpikudos irti alla olevasta kudoksesta.
3. Puuduta leikkausalue molemmin puolin arpea Lidocain 1% liuoksella.
4. Pidä sormi tai instrumentti arven alla ja leikkaa saksilla arpea pitkin kunnes virtsaputki tulee näkyviin. Varo vahingoittamasta arven alla olevia verekkäitä kudoksia.
5. Haavan reunapinnat tulee ommella synnytyksen jälkeen erilleen jatkuvalla intrakutaaniompeleella. Jos haavapinnat jätetään ompelematta, riskinä on, että haavan reunapinnat parantuvat yhteen.
6. Haavapintojen yhteen ompelu (refibulaatio) on Suomessa laitonta.

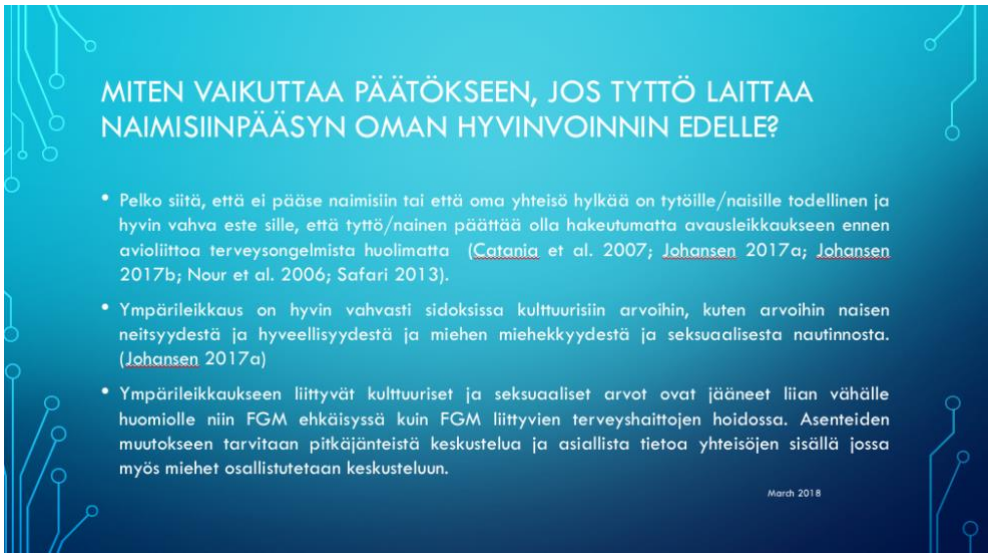
- Heidi Kytöaho, kätilö, HUS. 14.2.2018

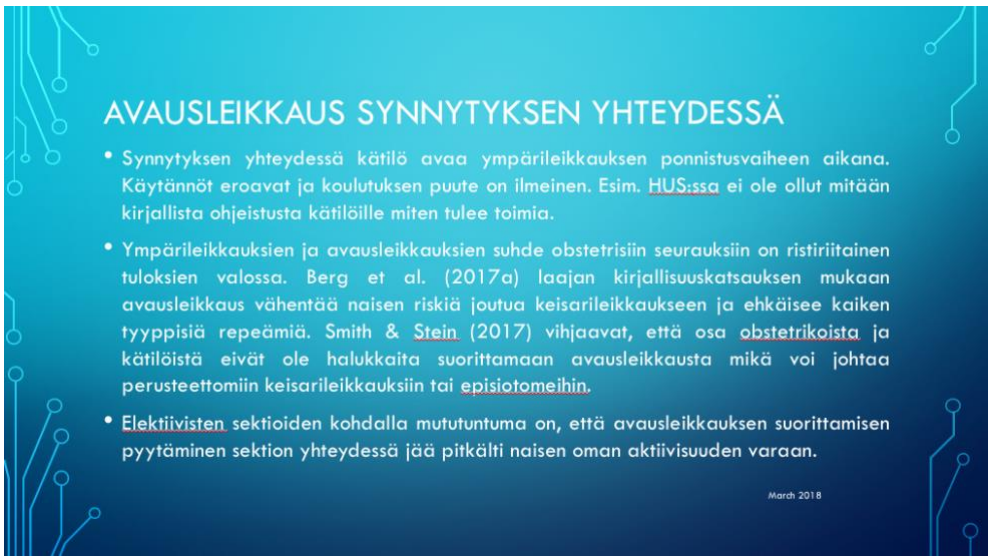
Appendix 7: A PowerPoint of the lecture about “the deinfibulation from the midwife’s point of view” by Heidi Kytöaho






OTETAANKO AVAUSLEIKKAUKSET PUHEEKSI TERVEYDENHUOLLOSSA?
MITEN OHJATA YMPÄRILEIKATTUA NAISTA?
• Suomesta puuttuu kokonaan virallinen kansallinen ohjeistus kuinka ympärileikattuja naisia tulisi ohjata ja missä, miten, milloin ja mitä tietoa ympärileikatuille naisille tulisi antaa. Suomen Gynekologiyhdistyksen ja Suomen Kätilöliiton kannanotossa (9/17) suosittelevat raskaana olevien ja mahdollisista oireista kärsivien ympärileikattujen naisten hoitoa julkisessa terveydenhuollossa. Ympärileikatut tytöt tulisi halutessaan ohjata erikoissairaanhoitoon avausleikkaukseen jo ennen yhdyntöjen aloittamista, jossa ulkosynnyttimien tilanteen arviointi tapahtuisi perehtyneen erikoislääkärin vastaanotolla. (Grénman & Rytkönen 2017.)
• Ympärileikatun naisen mahdolliset terveysongelmat tulisi vastaanotolla kartoittaa. Kartoituksessa tulee ottaa huomioon, että ympärileikatut naiset eivät aina tunnista, että jotkut terveysongelmat johtuvat ympärileikkauksesta. WHO (2016) ohjeistaa, että ympärileikattujen tyttöjen ja naisten tulisi saada terveydenhuollon ammattilaiselta asianmukaista ja puolueetonta tietoa avausleikkauksen odotettavista hyödyistä ja mahdollisista riskeistä sisältäen tiedon sen aiheuttamista anatomisista ja fysiologisista muutoksista
March 2018


MITEN VAIKUTTAA PÄÄTÖKSEEN, JOS TYTTÖ LAITTAA NAIMISIINPÄÄSYN OMAN HYVINVOINNIN EDELLE?
• Pelko siitä, että ei pääse naimisiin tai että oma yhteisö hylkää on tytöille/naisille todellinen ja hyvin vahva este sille, että tyttö/nainen päättää olla hakeutumatta avausleikkaukseen ennen avioliittoa terveysongelmista huolimatta (Catania et al. 2007; Johansen 2017a; Johansen 2017b; Nour et al. 2006; Safari 2013).
• Ympärileikkaus on hyvin vahvasti sidoksissa kulttuurisiin arvoihin, kuten arvoihin naisen neitsyydestä ja hyveellisyydestä ja miehen miehekkyydestä ja seksuaalisesta nautinnosta. (Johansen 2017a)
• Ympärileikkaukseen liittyvät kulttuuriset ja seksuaaliset arvot ovat jääneet liian vähälle huomiolle niin FGM ehkäisyssä kuin FGM liittyvien terveyshaittojen hoidossa. Asenteiden muutokseen tarvitaan pitkäjänteistä keskustelua ja asiallista tietoa yhteisöjen sisällä jossa myös miehet osallistutetaan keskusteluun.
March 2018


AVAUSLEIKKAUS SYNNYTYKSEN YHTEYDESSÄ
• Synnytyksen yhteydessä kätilö avaa ympärileikkauksen ponnistusvaiheen aikana. Käytännöt eroavat ja koulutuksen puute on ilmeinen. Esim. HUS:ssa ei ole ollut mitään kirjallista ohjeistusta kätilöille miten tulee toimia.
• Ympärileikkauksien ja avausleikkauksien suhde obstetrisiin seurauksiin on ristiriitainen tuloksien valossa. Berg et al. (2017a) laajan kirjallisuuskatsauksen mukaan avausleikkaus vähentää naisen riskiä joutua keisarileikkaukseen ja ehkäisee kaiken tyyppisiä repeämiä. Smith & Stein (2017) vihjaavat, että osa obstetrikoista ja kätilöistä eivät ole halukkaita suorittamaan avausleikkausta mikä voi johtaa perusteettomiin keisarileikkauksiin tai episiotomeihin.
• Elektiivisten sektioiden kohdalla mutuntuma on, että avausleikkauksen suorittamisen pyytäminen sektion yhteydessä jää pitkälti naisen oman aktiivisuuden varaan.
March 2018

AVAUSLEIKKAUSTEN ONNISTUMINEN JA KOMPLIKAATIOT?

- Pääsääntöisesti avausleikkaus on helppo toimenpide, jolla on vähän komplikaatioita ja toipuminen on nopeaa (Abdulcadir et al. 2014; Rouzi et al. 2001; WHO 2016). Systemaattista seurantaa esimerkiksi synnytyksen jälkeen ei kuitenkaan ei ole.
- Vaikka avausleikkaus vaikuttaisi helpottavan monia terveys- ja seksuaaliongelmia, avausleikkausten vaikutuksesta FGM:n aiheuttamien ongelmien korjaamiseksi on tällä hetkellä olemassa vain vähän luotettavaa tutkimustietoa.
- Komplikaatiot ovat yleensä vähäisiä kuten kipu ja epämukavuus leikkausalueella, virtsatie/haavainfektiot ja labioiden uudelleen yhteentarttumista (Berg et al. 2017b). Vaikka naiset ovat pääsääntöisesti tyytyväisiä leikkaukseen, on osalla naisista vaikeuksia hyväksyä muuttunut kehonkuva (Abdulcadir et al. 2014; Safari 2013; Smith & Stein 2017).

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MIKÄ ON PUOLISON ROOLI AVAUSLEIKKAUKSISSA?

- Kirurginen avausleikkaus saattaa olla tabu yhteisössä eikä siitä usein puhuta edes lähimpien perheenjäsenten, ystävien tai edes aviomiesten kanssa (Nour et al. 2006; Safari 2013, 156).
- Puolisoiden osallistuminen vaikuttaisi olevan tärkeää. Naiset, joiden puolisot osallistuivat avausleikkauksen päätöksentekoon ja prosessiin, olivat tyytyväisempiä ja heillä oli vähemmän ongelmia jälkikäteen. (Nour et al. 2006; Safari 2013.) Joissakin tapauksissa mies saattaa kuitenkin kieltää naista menemästä avausleikkaukseen ja tiukka introitus saatettiin nähdä edellytyksenä miehen seksuaaliselle tyydytykselle (Johansen 2017a; Safari 2013).
- Joissakin kulttuureissa kirurgista avausleikkausta ei nähdä edes vaihtoehtona vaan ainoa oikea tapa on yhdynnän yhteydessä penetraatiolla tehty "avaus". Miehen suorittama avaus liitetään miehen viriiliyteen and maskuliinisuuteen ja epäonnistuminen siinä saattaa altistaa miehen häpeälle ja yhteisöstä poissulkemiseen. (Johansen 2017a.)

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