

Women with Female Genital Mutilation and the Health Care Professionals who care for them:

Perceptions of Health care with an emphasis on Sexual Health

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Abstract

Female genital mutilation (FGM) is the procedure that intentionally alters or causes injury to the female genital organs for non-medical reasons. This term refers to all procedures that involve partial or total removal of the external female genitalia. More than 50,000 women born in a country practicing Female Genital Mutilation are now living in Sweden. Health Care Professionals treat these women every day with little knowledge or education on these women's culture or FGM in general. The sexual Health of these women is often ignored in the belief that these women cannot experience a normal healthy sex life. However these women due experience orgasm and many have an intact clitoris under an infibulation scar. Health Care professionals need a broader general education that includes an emphasis on cultural and patient centered care.

Keywords: Female Genital Mutilation, FGM, healthcare, culture, sexual health, orgasm,

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Introduction

My curiosity about Female Genital Mutilation started while watching a biography about Waris Dirie. After seeing the graphic depiction of the procedure performed on her in a desert at a very young age and her struggle when seeking care in Europe I was enraged and began to wonder why I had not been taught about this in my registered nursing program. I was even more curious about what I would need to know in order to properly care for women whom had undergone FGM. I could deduct that it was probable that I would meet a women with FGM in general care because I live in a city with a large refugee population. Female Genital Mutilation is performed using knives, scissors, pieces of glass, razor blades and scalpels. unless the procedure is performed by a medical professional no antiseptic or pain medications are used. When type III infibulation is performed the girls' legs are tied shut for a period of 10-14 days to immobilize her and allow scar formation. I found that over 50,000 women were living in Sweden who have been born in one of the countries that practice FGM. FGM is a cultural phenomenon that dates back before religion. Before I started this literature study I assumed that women with FGM were being dominated by their husbands and that they must be suffering. I assumed that these women could not have a voice or a choice in their daily lives and I would need to protect them from the horrible situations they must be experiencing at home because of FGM . I was also certain that they had a miserable sexual health and I was determined to help. As a health care provider (HCP) I had a desire to learn about this subject and hopefully help patients and HCP have a positive health care experience.

Background

Definitions

Evidence Based Care

Evidence based care is defined as: decisions within healthcare should be based on the best available, current, valid and relevant evidence. These decisions shall be made by those who give care and should be based on the care givers experience and factual knowledge within the frame for existing resources (Kajermo & Wallin, 2009). In the course literature for registered nursing students in Gothenburg there is only a few paragraphs written on FGM. During the obligatory lecture on reproduction and sexual health for registered nursing students, FGM was not mentioned.

Sexual Health

WHO defines sexual health as “a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled” (World Health Organization, 2013).

Many assume that women who have undergone FGM cannot experience sexual health (Leval, Widmark, Tishelman, & Ahlberg, 2010).

According to the World Health Organization (WHO) female genital mutilation is defined as procedures that intentionally alter or cause injury to the female genital organs for non-medical reasons. This term refers to all procedures that involve partial or total removal of the external female genitalia or any injury to the female genital organs for non- medical reasons and will be abbreviated as FGM (World Health Organisation Media Center Female Genital Mutilation (A), 2013).

There are three terms used to refer to the practice of removing part of the female genitalia.

Female genital mutilation (FGM) is the term used to emphasize the emotional, physical, and psychological violation inflicted on girls and women (Human Rights Watch, 2010).

Female genital cutting (FGC) is the term often used to emphasize the dangers associated with this practice (Human Rights Watch, 2010).

Female circumcision is a term that does not take into account the harmful effects of the procedure and is misleading therefor it implies that the practice is comparable to male circumcision even though FGM is a more invasive procedure that can lead to severe complications and has no medical or health benefit (Human Rights Watch, 2010).

When meeting and caring for women who have undergone a FGM procedure it is important to reflect and choose with care the term used when referring to the actual procedure. The term mutilation is strong for example and can cause communication between the care giver and patient to become difficult. In this essay the term adopted by health organizations and in written laws, female genital mutilation (FGM) will be used (Socialstyrelsen, 2005).

The majority of women, before leaving their own country, who have undergone FGM, see it as a source of pride and community acceptance. Western health care providers should be aware that women who have undergone FGM do not see themselves as different or mutilated and therefore can be offended by the word mutilation. This can lead to a fear of judgment, causing these women to not speak openly about any health concerns related to FGM (Braddy & Files, 2007).

Classification

The female external genitalia or vulva includes the clitoris that is covered by a thin hood of tissue called the prepuce, bartholin's glands located beside the vagina to produce a fluid mucus secretion, labia majora and labia minora also called the outer and inner lips. The urethra and opening to the vagina can also be seen externally. The internal female genitalia include the vagina, uterus, ovaries and fallopian tubes (Kimball Johnson, 2012) (Appendix I).

The World Health Organization (WHO), United Nations Children's Fund (UNICEF) and United Nations Population Fund (UNFPA) classify FGM into four different types, some of which having subcategories to closely capture the variety of procedures (World Health Organization, 2013).

- ✓ **Type I: Clitoridectomy** — Partial or total removal of the clitoris and/or the prepuce.
 - **Type Ia**, removal of the clitoral hood or prepuce only;
 - **Type Ib**, removal of the clitoris with the prepuce.

- ✓ **Type II: Excision** — Partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora. Major variations have been documented for which the following subdivisions are added:
 - **Type IIa**, removal of the labia minora only;
 - **Type IIb**, partial or total removal of the clitoris and the labia minora;
 - **Type IIc**, partial or total removal of the clitoris, the labia minor and the labia majora

- ✓ **Type III: Infibulation** — Narrowing of the vaginal orifice with creation of a covering seal by cutting and placing together the labia minora and/or the labia majora, with or without excision of the clitoris.
 - **Type IIIa**, removal and apposition of the labia minora;
 - **Type IIIb**, removal and apposition of the labia majora.
- ✓ **Type IV** — all other harmful procedures to the female genitalia for non-medical purposes, for example: pricking, piercing, incising, scraping and cauterization. (Appendix II)

Statistics

Even though there is false reporting about the amount of women living with different forms of FGM, it is thought that 15% of women with FGM are infibulated and 85% of all women with FGM have some form of excision or clitoridectomy (Talle, 2009).

In Iraqis Kurdish region the prevalence of FGM is 60-80%. Type I being the most common type performed with 99% prevalence. The common age for performing FGM is between four and seven years old (Yasin, Al-Tawil, Shabila, & Al-Hadithi, 2013).

Living in Sweden today there is approximately more than 50,000 women and girls whom come from a land that practices FGM. 5,000 of which are girls under the age of 7. This number is from 2009 appendix 3 shows numbers from 2012 (Talle, 2009)Appendix III.

It is estimated that 100 to 140 million women and girls worldwide have been subjected to one of the first three types of FGM. Women and girls at risk for undergoing FGM per year is estimated at 3 million or 8,000 per day. Recent prevalence data indicates 91.5 million girls above the age of 9 years old in Africa are living with the consequences of FGM (World Health Organization, 2013).

FGM Procedure

Female genital mutilation is performed across Central Africa, the Southern Sahara and in parts of the Middle East. On a lesser scale FGM is practiced in Indonesia, Malaysia, Pakistan and India. Immigration has led to FGM being seen in Europe, The United States, New Zealand, Canada and Australia (Womens Health, 2009).

In West Africa the most common age that a girl will undergo a FGM procedure is early puberty. Some tribes in Ethiopia and Eritrea circumcise babies one week after birth. In Somalia it is most common to undergo FGM between six and ten years of age (Talle, 2009).

In Africa FGM is usually performed by female community members. FGM can also be performed by health practitioners', male barbers, secret societies, herbalists and female relatives (UNFPA). In the Kurdish region of Iraq the procedure is performed by the villages' traditional birth attendants (Yasin, Al-Tawil, Shabila, & Al-Hadithi, 2013).

FGM is performed using knives, scissors, pieces of glass, razor blades and scalpels. Unless the procedure is performed by a medical professional no antiseptic or pain medicines are used. When type III infibulation is performed the girls legs are tied shut to immobilize her and allow scar formation for a period of 10-14 days (UNFPA).

Defibulation

During childbirth women must undergo defibulation, the process of having the scar from infibulation opened. The procedure defibulation is often performed before sex for the first time by the husband or a female family member either with a cutting instrument or with the penis being forced into the small vaginal opening (Talle, 2009).

Refibulation

In their home countries after childbirth they are reinfibulated or re sewn. Note that in Sweden it is against the law to reinfibulate women after childbirth (Talle, 2009).

History, Culture and Religion

FGM comes from long and deep cultural traditions and beliefs. Some examples of these beliefs are that women cannot become pregnant or have healthy children without the procedure, the clitoris will grow so large that it will prevent a penis entrance into the vagina or block a child's birth, female genitalia is considered dirty and ugly and must be removed or a girl is unmarriageable, and it is a belief that those women who have undergone FGM have high morals, are not promiscuous, and are virgins when married (Talle, 2009).

The procedure has been practiced for centuries and is linked with the moment a girl becomes a woman. It is a rite of passage into adulthood. The ceremony is kept from outsiders, especially men. The procedure itself is proof that the girl has the knowledge necessary to be a woman, wife and mother and is worthy of belonging to the community (Kaplan, o.a., 2013).

Many assume that FGM is performed due to religious beliefs though neither the Koran nor Bible mentions it (Jirovsky, 2012). FGM has existed within social and cultural practices before Christianity and Islam. It is thought that FGM was practiced in the time of the Egyptian pharaohs due to the term pharaonic circumcision. FGM has been documented in the historic literature of seamen's voyages. The existing practice of FGM is found often parallel with the propagation of Islam and is the basis for the false belief that FGM is an Islamic belief (Talle, 2009).

There are many organizations around the world that have a purpose to end FGM. It can be noted that foot binding in China was practiced for more than one thousand years but was abandoned within one generation's time due to the concept that a deep rooted tradition like foot binding or FGM is based on parents basing a decision from guessing and how others are doing at the same time. This saying, that a tradition is only good as long as everyone else is practicing it otherwise the person will be alone in the practice which only gives negative consequences (Essén, 2008).

The most common reason for performing FGM in Kurdish regions is cultural tradition (Yasin, Al-Tawil, Shabila, & Al-Hadithi, 2013).

Clitoridectomy was practiced in Western Europe and The United States as recent as the 1950's to treat "ailments" such as epilepsy, hysteria, masturbation and lesbianism (UNFPA).

The Male View of FGM

Research of the male population in communities practicing FGM is very few. The research that is available describes the opinions and complications of men in these communities.

Sixty men were part of a research project in Sudan. They stated that some of the male complications from FGM included; difficulties with penetration, wounds/bleeding/inflammation of penis from the small vaginal opening, and that women have pain and suffer which is negative for the man. To be socially accepted and for tradition were reasons some men would prefer to marry a woman who had undergone FGM. Avoiding problems during delivery and more sexual enjoyment/avoiding suffering during sex were the reason they would prefer a woman who had not undergone FGM (Almroth, o.a., 2001).

One of the topics that emerged after interviews in Bobo-Dioulasso and Burkina Faso was marital conflict due to painful sexual intercourse. An interesting finding was that FGM was performed to keep women faithful and women use herbs and lotions to keep men sexually satisfied (Jirovsky, 2012).

It was revealed in a research study in Gambia of 993 men that only 8% of men take part in the decision making process of FGM. It is women who dominate the decision making process with 75.8%, 10% of relatives or community members make the decision and 6.2% of men make the decision with their wives (Kaplan, o.a., 2013) .

Health Risks

Short Term Complications include: hemorrhage, shock, pain, urinary retention, injury to adjacent tissue, infection, fracture or dislocation of bones and difficulties healing

Long Term Complications include: difficulties with micturition(urination), hematocolpos (accumulation of menstrual blood in the vagina), recurrent urinary tract infections (UTIs), chronic pelvic infections, occluding scar tissue, infertility, vulvar abscesses, neurinoma, keloid scars, dermoid cysts, calculus formation, fistulae, difficulties with menstruations (as severe as lasting more than ten days with vomiting despite non-steroidal anti-inflammatory medications), dysmenorrhea (menstrual cramps), apareunia (penis unable to penetrate vaginal opening), dyspareunia (pain with sexual intercourse), increased risk of HIV transmission (caused by tearing and wounds with vaginal penetration), sexual complications and psychosocial complications(FGM Information for Health and Child Protection Professionals, 2011) (World Health Organization, 2013) (Holmberg, 2009) (Burke, 2011) (Nour, Michels, & Bryant, 2006).

Laws

In Sweden

As of June 1, 1998 The Swedish law titled Ban of female circumcision (1982:316) was changed to Ban of female genital mutilation (1998:407).

1 § Procedures on the female external genitalia in order to mutilate or make other permanent changes to them (FGM) may not be performed, regardless of whether consent has been given for the procedure or not. 2 § A person who violates 1 § shall be sentenced to imprisonment not exceeding four years. It will be considered an aggravated felony if the offense results in loss of life, serious illness or otherwise involves a particularly reckless behavior. A felony offense shall be sentenced to imprisonment for not less than two nor more than ten years. Attempt, Preparation, conspiracy and failure to disclose this offense is

punishable in accordance with Chapter 23 of the penal code. (Svensk författningssamling, 1998)

According to socialtjänstlagen care givers must report immediately to the welfare department any suspicion or knowledge of a child who may or has undergone FGM. (Regeringskansliets rättsdatabaser , 2001)

In the World

The 18th of December 1979 the United Nations adopted the Convention on the Elimination of all forms of Discrimination against women. All nations who have accepted this Convention are bound to follow the provisions of every Article. These nations are obligated to work towards modifying social and cultural patterns that lead to the discrimination of women. Four of these articles address FGM. (United Nations, 2013) Iran, Nauru, Palau, Somalia, Sudan and Tonga have not ratified this convention and The United States is the only country who has signed but not ratified this convention. (Blanchfield, 2011)

Article 1 For the purposes of the present Convention, the term "discrimination against women" shall mean any distinction, exclusion or restriction made on the basis of sex which has the effect or purpose of impairing or nullifying the recognition, enjoyment or exercise by women, irrespective of their marital status, on a basis of equality of men and women, of human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.

Article 5: State Parties shall take all appropriate measures: (a) To modify the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of prejudices and customary and all other practices which are based on the idea of the inferiority or the superiority of either of the sexes or on stereotyped roles for men and women

In July of 2003 the Maputo Protocol was adopted by the African Union with the name Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa. Several articles address and forbid FGM. (African Commission on human and Peoples rights, 2003) Eighteen African Countries have not ratified this protocol; Algeria, Botswana, Burundi, Central African Republic, Chad, Egypt, Eritrea, Ethiopia, Madagascar, Mauritius, Niger, Sahrawi Arab Democratic Republic, Sierra Leone, Somalia, Sao Tome & Principe, Sudan, South Sudan and Tunisia (FIDH, 2013).

Important Concepts

Patient Centered Care

Patient centered care has its base in that health care professionals can contemplate their own set of values and ethics, can put themselves into another person's perspective and is capable to change and adapt their approach based on the needs of the patient. This involves health care professionals having knowledge and understanding of the patient's expectations, wishes and actual needs (Sellgren, 2009). When dealing with patients with FGM Health care professionals focus on the procedure itself and do not overcome their feelings of disgust to properly see the woman and her family as a whole person (Berggren, Bergström, & Edberg,

2006) (Leval, Widmark, Tishelman, & Ahlberg, 2010) (Widmark, Tishelman, & Ahlberg, 2002).

Transcultural care/ Cultural diversity

Transcultural care is defined as:

“a formal area of study and practice in nursing, focused upon comparative holistic cultural care, health and illness patterns of individuals and groups with respect to differences and similarities in cultural values, beliefs and practice with the goal to provide culturally congruent, sensitive and competent nursing care to people from diverse cultures (Jirwe, Momeni, & Emami, 2009).”

A persons cultural background is influenced by different aspects of their life for example; beliefs, language, religion and views on family. Specific knowledge on the cultural background of treated patients is essential for good health care (Jirwe, Momeni, & Emami, 2009). In relation to the fact that so many immigrants from different cultural backgrounds are now being cared for by HCP from western cultures it is imperative that a cultural awareness is part of health care.

Emily Burke (Burke, 2011) presents Dr. Heeseung Choi's Theory of Cultural Marginality in her paper on applications of nursing theory for clinical care. This theory is based on the patients struggle to accept a new culture without abandoning their own culture and can guide HCP in understanding and giving better care to patients from other cultures.

AIM:

This literature study has an aim to bring into focus the cultural, medical and sexual difficulties and situations facing HCP and patients with FGM and to help HCP find a way to provide better patient centered care for these women.

Problem area:

Women with FGM are met by HCP with lack of cultural, sexual and medical education about FGM. This leads to women with FGM not seeking health care and relying on cultural traditions that can lead to a continuation of FGM. I hope to give HCP a better understanding and knowledge of the women with FGM culturally, medically and sexually, so they can treat these women using patient centered care.

Method:

Literature review:

The method used to conduct this research paper was a literature review. This literature based research paper uses text as its material, with the intent to deepen and develop knowledge (Lyckhage, 2006,2012). This literature review was based on a process of critically evaluating and summarizing previously published scientific research articles (Lyckhage, 2006,2012). Scientific articles are one of four types of scientific documents and they have a very high status among scientists and researchers (Backman, 2008). These articles were published in,

the most common, important and useable reference base, an international scientific journal. Prior to publishing these articles go through a strict evaluation process conducted by an editorial board consisting of the most prominent researchers in the journals scientific field. These researchers examine and evaluate the articles for quality. In many Journals a second evaluation of quality is conducted by a team known as referees whom consist of prominent independent researchers within the articles specific scientific field (Backman, 2008) Appendix IV.

Search Data bases:

The literature search was conducted using the search databases PubMed, Cinahl, and Scopus. Several reference databases were chosen because one database does not contain all known research within a scientific area. PubMed was chosen because it is the world's largest medical reference database and CINAHL (cumulative Index to Nursing and allied Health) was chosen because it is a database covering the Health and Care sciences (Backman, 2008). Scopus was chosen because it is a database which includes peer reviewed literature in the research fields of science, technology, medicine, social science and the arts and humanities (ELSEVIER B.V., 2013) .

Search Method:

Relevant articles were chosen using different search terms that have a background in the chosen subject area. Search terms that were used included; female genital mutilation, nursing, sexuality, sexual health, orgasm, men. The search technic Boolesk was used in order for the data base to combine two search terms (Östlundh, 2006,2012). First articles were chosen from their titles. Those articles abstracts were then read for relevance. If an article was chosen after this process they were then read in detail for quality. Quality was determined using Fribergs fourteen questions for review of qualitative studies and thirteen questions for review of quantative studies (Friberg, 2006,2012). A secondary search was done using the reference list of already chosen articles, authors of interest last name and suggested from already read article abstracts. Those articles that were determined to be of high quality, and met the aim of this literature review were used (Östlundh, 2006,2012)Appendix V.

Ethical Considerations

All participants in the chosen articles to this literature review were willing to participate. They were assured anonymity. Confidentiality was achieved by using code numbers in all analysis. In interview/ qualitative studies tape recording were destroyed or patient/personal identifiers were removed or disguised. Written consent was obtained from those who chose to participate in the studies. Six of the ten articles used included had ethical approval of an ethics committee before the study began.

Interviews were conducted where the participants felt most comfortable, for example in their own homes (Lundberg & Gerezgiher, 2006). When interpreters' were used or needed they were female and/or familiar to the women. This is obligatory because the women cannot and will not discuss such sensitive and private matters with an investigator they do not trust (Berggren, Bergström, & Edberg, 2006) (Carroll, o.a., 2007) .

Inclusion/Exclusion Criteria

Articles about women with FGM and their perceptions of health care in a western culture were chosen. The first thought was not to include childbirth experiences but because of too few articles being available those articles were also accepted. Articles with both positive and negative perspectives were included for a better, well rounded understanding of the patients' experience. Both patients' and health care providers' perspectives were used. This was decided in a hope of seeing both limits and strengths in the healthcare experience. The subject area of FGM is not well researched and this could be in part to the sensitivity of the subject. For this reason all health care professionals were included because there were not enough articles of high quality with only a nurses' perspective. No articles written before 2001 were chosen in order to have the most recent evidence. Only articles written in English were accepted. Articles were not accepted if their aim or result involved infant complications at birth or mortality in regards to FGM. Articles were not accepted if the participants were less than eighteen years of age.

Result

Patient Perspective

Emotions

Patients described feelings of fear and anxiety when discussing situations regarding childbirth. They felt fear of the entire birthing experience in relation to the fact they had undergone infibulation. They feared incontinence and death was associated with cesarean birth which increased feelings of fear and anxiety. Some women even ate less to avoid a cesarean birth (Berggren, Bergström, & Edberg, 2006) (Lundberg & Gereziher, 2006).

“When I was pregnant the first time I had no idea about the problems during childbirth. In my country, women do not speak about delivery and its hardships. I faced the complication in my second pregnancy I started to think about my delivery... would it become difficult or not?... What would happen to me if the baby came out too quickly? That’s why I felt fear (Lundberg & Gereziher, 2006).”

“I told the midwife that I was circumcised and sutured. The midwife had to cut and open the stitches during my delivery. I was worried and feared how she was going to manage it (Lundberg & Gereziher, 2006).”

Worry was an emotion expressed about HCP caring for them without knowledge of FGM and about being defibulated during delivery. They felt insecure when being treated by HCP without knowledge of FGM and shock when they realised the HCP caring for them had no knowledge of how to defibulate or “cut” a woman with FGM (Berggren, Bergström, & Edberg, 2006) (Lundberg & Gereziher, 2006).

The women expressed feelings of being vulnerable and helpless, especially when they perceived the HCP as having no knowledge of FGM. They felt like study objects for curious HCP. Frustration was felt due to HCP not listening and being told what to do by HCP and a

general sense of inferiority (Berggren, Bergström, & Edberg, 2006) (Lundberg & Gereziher, 2006).

“During delivery we have to ask the midwives to cut, sometimes the midwife calls a doctor to find out whether she should cut or not. During this argument the baby pops out causing too much tearing and bleeding. It is very frustrating to be confronted with a situation where the professionals appear as though they do not have control and are unsure of what is to be done (Lundberg & Gereziher, 2006).”

The women experienced feeling double shame in their lives. The shame they would experience from not having FGM in their communities and the shame they feel now in their new communities (Lundberg & Gereziher, 2006).

“In my country all women are circumcised. Therefore, no one feels different and they never think about what would happen (Lundberg & Gereziher, 2006)”

When I went to the parent and child center, I discovered that I was different from Swedish women because of my circumcision (Lundberg & Gereziher, 2006)”

The women felt they had suffered as children because of FGM, remembering feeling abandoned, betrayed and having no choice but feel they also suffer as women during gynecological exams and birth. They explained suffering from physical complications and the pain of defibulation (Berggren, Bergström, & Edberg, 2006) (Lundberg & Gereziher, 2006).

“I and other women who have not been opened before delivery suffer most. We need to be opened at delivery, but the midwives don’t know how to cut. They wait until the head of the baby is down and then they cut in a hurry in all directions, often several cuttings. They are not careful. I think that they see us as already being destroyed (Berggren, Bergström, & Edberg, 2006).”

Physical complications

Patients had experienced physical complications that were related to FGM. They discussed inflammation around the wound, painful menstruation, difficulties with their sexual life, painful vaginal exams, especially if performed by a male, extreme pain during and after delivery, infected wounds in the genital area, bleeding and urine and/or fecal incontinence (Berggren, Bergström, & Edberg, 2006) (Lundberg & Gereziher, 2006).

According to Nour’s study on defibulation to treat Female Genital Mutilation (Nour, Michels, & Bryant, 2006)

The primary indications of forty patients who underwent defibulation were: dysmenorrhea, pregnancy, apareunia, dyspareunia, chronic vaginitis, and engagement (Nour, Michels, & Bryant, 2006).

The secondary indications for those patients were: apareunia, difficulty urinating, dyspareunia, engagement and dysmenorrhea

According to an analysis of the first twelve months at a specialist clinic for FGM (Momoh, Ladhami, Lochrie, & Rymer, 2001). One hundred and eight women with FGM type III, type I, and type II stated remembering having acute complications of: severe pain, especially with urination, localized infection/abscess, heavy bleeding, acute urinary retention, septicemia. These women received care at a specialized clinic in London for patients with FGM and have been diagnosed with chronic complications consisting of: dysmenorrhea; one requesting defibulation, poor urinary flow/painful urination, dyspareunia for >3 months; two requesting defibulation, recurrent >3 urinary tract infections ; five requesting defibulation, keloid scar, dermoid cysts difficulty conceiving; 2 requesting defibulation, haematocolpos, requiring widening of vaginal orifice and urinary incontinence. Twenty two of those women had informed their general physician (GP) that they had undergone FGM but other women did not want their GP to know. The twenty two women had told their GP because of an underlying medical problem those being; recurrent urinary tract infection, dyspareunia, defibulation for marriage , dysmenorrhea , infertility, bedwetting at age 23 .

Eighty four of 108 women were referred to the clinic by their midwives because of recurrent urinary tract infections and fear of birth through a small opening .

Physical complications of fifteen women who had undergone defibulation were; sexual intercourse for the first time, dysmenorrhea, urinary and vaginal infections and improve flow of urine and menstrual flux (Catania, o.a., 2007).

Defibulation/Refibulation

Patients expressed mixed views on refibulation. In their home countries all women are refibulated after birth and they do not want to be different by refusing refibulation. Some women also experienced extreme pain by not being refibulated in regards to the exposed genitalia rubbing against their underwear (Berggren, Bergström, & Edberg, 2006) (Lundberg & Gereziher, 2006).

“...The midwives refuse to resuture me. I just ask for a few stitches, not to have an open wound. I got an infection once. I also feel pain when walking, my underwear hurts (Berggren, Bergström, & Edberg, 2006) .”

Some women asked to be defibulated but were refused by HCP. They wished to be defibulated during pregnancy and to stay defibulated to prevent suffering. They felt that HCP had no knowledge on how to perform defibulation and had to instruct midwives on how to perform the procedure (Berggren, Bergström, & Edberg, 2006) (Lundberg & Gereziher, 2006). Forty patients who underwent defibulation at a clinic were 100% satisfied (95%CI 87.7-100) (Nour, Michels, & Bryant, 2006). Other women had been defibulated by their husbands or birth attendants in their home country using knives or razor blades (Berggren, Bergström, & Edberg, 2006) (Lundberg & Gereziher, 2006) (Nour, Michels, & Bryant, 2006) (Momoh, Ladhami, Lochrie, & Rymer, 2001).

Communication

Patients stated positive communications experiences with HCP when the HCP was seen as being available, showing patience, smiled, showed kindness and showed an interest in the women's culture/language (Carroll, o.a., 2007).

Non-verbal communication was often described as negative. Patients described HCP having looks of disgust, seeming like they had seen something strange and patients often described being stared at by several members of the health care team at the same time. They describe situations when HCP stood and talked about the woman without speaking to her. Some woman even missed medical appointments after receiving negative comments that made them feel judged (Berggren, Bergström, & Edberg, 2006).

“They didn't ask me, but I heard how they talked to each other that I didn't look so severely damaged after all. I thought that they might have seen a lot of other women before. Another time they looked at me there with faces full of disgust. But nobody has even asked me about it. But they are kind. I think that they just don't dare to ask (Berggren, Bergström, & Edberg, 2006).”

“Before and at my first two deliveries the HCP were very nice, but then there was like a change in attitudes.... A midwife said, are you here again already? We'll probably see you here next year and next year again. Then when I came back I didn't feel good (Berggren, Bergström, & Edberg, 2006).”

Women discussed the difficulties and feelings they had discussing FGM and sex. Some reasons women didn't discuss these issues with HCP were: shame, privacy, fear of being unaccepted, afraid others would not understand and embarrassment (Berggren, Bergström, & Edberg, 2006) (Carroll, o.a., 2007) (Momoh, Ladhami, Lochrie, & Rymer, 2001) (Nour, Michels, & Bryant, 2006) (Lundberg & Gereziher, 2006)

“You suffer and you can't say anything because no one talks openly about pain related to sex. Shortly, it is shameful (Lundberg & Gereziher, 2006).”

Many women felt that no HCP had asked them about FGM or if they had undergone FGM, however they implied that they wish HCP took up the subject because it goes against their culture to take it up themselves (Lundberg & Gereziher, 2006) (Berggren, Bergström, & Edberg, 2006).

Patients' perspective of HCP education/knowledge

Patients described that a majority of HCP had little to no knowledge of FGM. They felt they encountered this when requesting defibulation and during birth. They felt they had instructed midwives on how and when to “cut” during their own childbirth (Berggren, Bergström, & Edberg, 2006) (Lundberg & Gereziher, 2006).

“There are many Somali women here in Sweden, so they must have the experience. This was what I thought. I remember the delivery as a long fight from my side. And then I mean not only fighting with the delivery of my baby but fighting in order to get the staff to understand how I would like it. In Somalia, the midwives know how to deal with us. We need to have help because we are sutured. We can’t become like Swedes, and we can’t deliver like swedes. We are more afraid because we are sutured (Berggren, Bergström, & Edberg, 2006).”

Culture

Catania (Catania, o.a., 2007) states in semi-structured interviews of fifty eight young immigrant women that they expressed in their own countries feeling social acceptance, felt family love and thought that FGM/C testified beauty and courage. Once living in a western culture this transformed to negative meanings. They understood that FGM was a negative word and others thought they were victims of family violence and barbarity. They no longer had a sense of beauty.

Women with FGM who seek health care are faced with overcoming cultural differences also. It was discussed that being seen by a male HCP is only acceptable in acute situations. According to these women’s’ religion they should not be treated by a male HCP. The experience of having a male HCP can be experienced as sexual abuse. The women expressed at they would like HCP to understand FGM is a very common part of their culture. They believe that all women in their culture have undergone FGM and they do not know the difference of not having FGM (Berggren, Bergström, & Edberg, 2006) (Lundberg & Gerezgiher, 2006). These women said they will only share deep and private concerns with a female HCP and will only seek health care from a female HCP (Carroll, o.a., 2007). An issue with accepting and understanding a new culture was that the only time they interacted with Swedish people was for work or business (Berggren, Bergström, & Edberg, 2006). A large part of their culture that the women missed the most and wanted to continue was the support and network of the female community. It is very common to be taken care of forty days after birth by female friends, family and community members. Women gather often with their female friends and family members to discuss problems and get advice (Berggren, Bergström, & Edberg, 2006). The women also wanted to continue using herbs and incense for the vaginal tightening properties and pleasant smells (Berggren, Bergström, & Edberg, 2006).

Health Care Experiences

Positive health care experiences

Positive health care experiences could be reached when the patients felt their HCP had knowledge of FGM or had worked in Africa (Carroll, o.a., 2007). It was considered good health care when the patients received a physical examination and medicine (Carroll, o.a., 2007) (Lundberg & Gerezgiher, 2006). Knowing how the new health care system worked; how to make appointments, where the clinics were located, explanations of procedures (why and how) were considered factors in good health care (Carroll, o.a., 2007). HCP Showing interest in their patients’ culture, being kind, private, sensitive, patient and having access to a

female interpreter were also factors in good health care. Women expressed a need for health care workers from their own culture to hold health education meetings (Carroll, o.a., 2007).

Negative health care experiences

Negative health care experiences were explained as; feeling rushed, waiting a long time, having many different HCP, demonstrating frustration or impatience and depersonalized care (Carroll, o.a., 2007). The largest theme of negative health care experiences were HCP not having knowledge or education regarding FGM (Berggren, Bergström, & Edberg, 2006) (Carroll, o.a., 2007) (Lundberg & Gereziher, 2006).

Sexual Health

The women stated that is common to experience some difficulties in regards to sex. However it is unacceptable to discuss sex with anyone other than their husbands. The most common themes regarding sexual difficulties were pain(dyspareunia) due to the vaginal opening being too small or that their husbands were unable to penetrate the vaginal opening (apareunia). Many women had to be “cut” (defibulated) to have sexual intercourse. This was done either on their wedding nights or several days or months later. Their husbands or a birth attendant used a knife or razor blade to open the scar. (Berggren, Bergström, & Edberg, 2006) (Lundberg & Gereziher, 2006).

“It was very difficult for my husband to penetrate. It took many days before he could do it. Before my marriage, I had no idea that it would be hard and painful. After the first contact with my husband I knew that I was sutured and that it had to be opened (Lundberg & Gereziher, 2006).”

The women did explain that love, understanding and harmony did make sex enjoyable for them (Lundberg & Gereziher, 2006).

Four groups of women participated in Catania’s (Catania, o.a., 2007) study on sexuality, questions included; perception of own body/body of women without FGM, sexual fantasies and pleasure. These women were also examined by a female gynecologist to determine which type of FGM procedure they had undergone.

Group A consisted of 137 married/widowed/divorced immigrant women with different types of FGM and reported that sex gives them pleasure. Ninety five women reported orgasm with vaginal sex and 107 reported orgasm also with manual masturbation by their partner.

Group B consisted of fifty seven unmarried sexually active women with different types of FGM and fifty three reported orgasm with vaginal sex and twenty reported orgasm also with manual masturbation by their partner.

Group C consisted of fifteen Type III infibulated women that had undergone defibulation, some of whom had an intact clitoris under the infibulation scar. Eight of the women from Group C had sex before defibulation and reported a decrease in dyspareunia after the procedure. Fourteen reported orgasm after the procedure.

Physical events of orgasm were described as: involuntary pleasurable rhythmic contractions of the vagina, pulsations of the internal genitals and a feeling of warmth all over the face and body. Descriptions of the psychological orgasm were: uncontrollable words or sounds complete abandoning of the body, complete loss of control and feelings of exploding or melting.

A fourth Group D completed the Female Sexual Function Index and consisted of fifty seven infibulated women and a control group of fifty seven women who have not undergone FGM (3 Somali, 54 Italian). Statistically significant increase in the domains of desire, arousal, and satisfaction were found in the group of *infibulated* women $P < 0.001$ and orgasm $P < 0.04$.

Nours study (Nour, Michels, & Bryant, 2006), of the results of forty patients that had undergone defibulation, found that 48% had an intact clitoris under the infibulation scar. One hundred percent (95% CI 87.7-100) of the participants' husbands were satisfied with their wives' new appearance and stated their sexual life had improved.

Health Care Professionals Perspective

Emotions

The HCP stated feeling very strong emotions when encountering women with FGM. The feelings were described as sorrow, pity, anger, hatred and being furious (Leval, Widmark, Tishelman, & Ahlberg, 2010) (Widmark, Tishelman, & Ahlberg, 2002). One women said "*why does it arouse such hate, I mean it takes a lot not to show your innermost aggressions.*" They also stated feeling deep empathy, protectiveness and wanting to treat these women with extra care. They stated identifying with these patients as women and wanting to be kinder and more careful, one HCP said "*I take care of them just like all the others and perhaps try to be more empathic, more present and kinder..*" (Widmark, Tishelman, & Ahlberg, 2002).

Physical complications

HCP state that FGM causes difficulties in caring for these women. It is impossible to insert intrauterine monitoring devices during delivery or for other diagnostic purposes. It is nearly impossible to perform internal vaginal exams. It is impossible to obtain sterile urine specimens because women with infibulation cannot clean the urethra. Catheterization is very difficult because the urethra cannot be visualized. The HCP discuss it is difficult to recognize the genital anatomy due to scar tissue. Tissue and scar damage can be invisible to the naked eye which can cause a false belief that the anatomy is undamaged (Widmark, Tishelman, & Ahlberg, 2002).

In a study of 769 HCP 458 had met a patient with FGM and 302 had met a patient with a physical complication related to FGM. Those complications were; dyspareunia, dysmenorrhea, obstetrical difficulties, urinary tract- related problems and psychosexual difficulties (Tamaddon, Johnsdotter, Liljestrang, & Essén, 2006).

Defibulation/Refibulation

In many cases the patient wants "cut" (defibulated) and the HCP is unsure: This causes more stress for the HCP. The HCP refuses to defibulate when asked by the patient during delivery, assuming the tissue is normal and this causes more rupturing "she wanted to be cut but she wasn't and she ruptured...so our way of assessing doesn't work with those women." The HCP feel unsure of when to defibulate and how to defibulate. "And it is disgusting to cut, and especially upwards" (Widmark, Tishelman, & Ahlberg, 2002).

"It's always the same, as soon as we have a circumcised woman, how should we cut and what should we do?...it becomes sort of a big discussion between midwives and the doctor, yes there are several people involved in the discussion (Widmark, Tishelman, & Ahlberg, 2002)."

HCP feel it is the men demanding reinfibulation at deliveries.

"...there the man was really determined that she should be sewn back together again, and he was the one who decided and ...she also wanted it to be done, and his mother was there, and her mother was there and everyone was there (Widmark, Tishelman, & Ahlberg, 2002)."

The HCP at prenatal clinics describe that patients come to the clinic if they are left unsutured after the delivery, complaining of pain so severe that they could not wear underwear (Widmark, Tishelman, & Ahlberg, 2002).

Communication

HCP feel language barriers exist between themselves and their patients with FGM. They try to establish a connection with these patients when their husbands leave the room by using gestures and non-verbal communication. HCP feel unsure of how to communicate on the subject of FGM and do not want to mention if the patient is or may have undergone FGM. HCP wanted information about their patients sexual health but none asked about it (Leval, Widmark, Tishelman, & Ahlberg, 2010) (Widmark, Tishelman, & Ahlberg, 2002).

"I don't ask about it, no I don't think...it feels wrong...we never start by asking anyone else...It feels wrong to ask this woman straight off because then you'll lose the first important contact with her... (Widmark, Tishelman, & Ahlberg, 2002)."

HCP discuss not being able to control their facial expressions when encountering women with FGM or their feelings of aggression "but your eyes and body language..that isn't anything we can decide to control (Widmark, Tishelman, & Ahlberg, 2002)."

"I remember well the first patient I had, her vagina wasn't wider than a pencil...you kind of try to deal with your facial expression even though you don't really know what it is that you see (Widmark, Tishelman, & Ahlberg, 2002)"

Perception of Education/Knowledge

In a cross sectional study between 2001 and 2004 of 280 HCP there was a statistically significant increase ($P < 0.001$) in the number of cases of FGM but a statistically significant decrease ($P < 0.001$) in HCP level of knowledge of FGM and in a study of 769 HCP 217 reported a self-estimation of adequate knowledge of FGM. There was a statistically significant greater interest ($P 0.001$) of the subject FGM with female HCP and a statistically significant higher ($P 0.009$) number of female HCP who detected cases of FGM. (Tamaddon, Johnsdotter, Liljestrand, & Essén, 2006) (Kaplan-Marcusan, Torán-Monserrat, Moreno-Navarro, Castany Fábregas, & Munoz-Ortiz, 2009).

There was a statistically significant increase ($P < 0.05$) in how the HCP thought FGM should be approached, those being: educate, report to authorities and educate and report to authorities (Kaplan-Marcusan, Torán-Monserrat, Moreno-Navarro, Castany Fábregas, & Munoz-Ortiz, 2009).

HCP feel they have not been educated about FGM. They state they must seek knowledge themselves through seminars and lectures. Midwives discuss that Doctors are not more knowledgeable and they cannot ask them for advice on when or how to defibulate. They feel they do not have adequate knowledge of the changed anatomy of the women with FGM. HCP state there are no guidelines in the departments they work in on how to care for women with FGM and they only receive information on what not to do according to the law (Widmark, Tishelman, & Ahlberg, 2002).

Kaplan-Marcusan et.al (Kaplan-Marcusan, Torán-Monserrat, Moreno-Navarro, Castany Fábregas, & Munoz-Ortiz, 2009) found a statistically significant ($P 0.001$) difference between HCP who stated they knew what FGM was and correctly identifying FGM.

Perception of FGM Culture

The HCP expressed wanting to have more understanding of women with FGM. They understand that cultural differences make encounters with women with FGM complex. They believe because of cultural barriers it is impossible to find answers to their questions on FGM. They believe women are powerless and passive in the FGM culture and believe their own culture is knowledgeable and the women from cultures with FGM are ignorant (Leval, Widmark, Tishelman, & Ahlberg, 2010) (Widmark, Tishelman, & Ahlberg, 2002)

Perception of Men

The HCP felt feelings of furiosity, anger and hatred towards the tradition, men and husbands of this culture and their religion. The HCP describe men as awful and do not trust when they see men being gentle and caring. They describe men in the delivery room as sensitive. They also describe that most men appear shocked at seeing how difficult it is for their wives in delivery, some men even cry and promising to not let the same thing happen to the baby if it is a girl. The husbands were against refibulation after delivery (men who were alone with

their wives, no family in room) (Leval, Widmark, Tishelman, & Ahlberg, 2010) (Widmark, Tishelman, & Ahlberg, 2002)

“In the beginning when I didn’t have knowledge I believed that the whole thing was the men’s fault, and then you get so aggressive (laugh) when you think, ‘yeah, so it’s his fault.’ Until I understood that it isn’t so at all, but instead it’s just like confirmation is for us. You have to be confirmed to be part of the group. Yes, well, it’s not like that but as an example anyway. Or a baptism for most people...And in their countries it’s so important to be circumcised. It’s done in order to be part of the group. And if you turn the tables they you think, of course, you would get circumcised, or what, otherwise you’re shunned (Leval, Widmark, Tishelman, & Ahlberg, 2010).”

“ I had a patient a couple of weeks ago who absolutely wanted to be reinfibulated. She had given birth to six children and wasn’t going to have anymore, and now it was time to be sewn up and she was really angry with me because she said, “I know that you can help me because I need..” She really knew exactly, I need to get a referral from you so that I can do this at a hospital and you can help me.”her husband, he stood next to her and stomped and said “No, she is too crazy about this and I don’t think she needs to do this at all... (Leval, Widmark, Tishelman, & Ahlberg, 2010)”

“....but it surprised me what he said, because I tried to point out that it (FGM) was done for the sake of men but he said it wasn’t like that. “It’s not us that want it” he said “ it’s the women, they are so strong (Leval, Widmark, Tishelman, & Ahlberg, 2010).”

“And she said that she was circumcised and she said “if it is a girl I promise you she won’t be circumcised”..but then we said alright but your husband though..”No it’s me that decides (Leval, Widmark, Tishelman, & Ahlberg, 2010).”

“ It’s difficult because you are so angry. You get so...get so enraged at the whole situation, at the whole culture for something.. a little primitive, sometimes it seems that I only feel upset. How the hell can they subject women to that (FGM), to this..I become so furious at men ... (Leval, Widmark, Tishelman, & Ahlberg, 2010).”

HealthCare Experience

The HCP describe the health care experience as stressful. They feel greater stress from not having adequate knowledge and the added pressure from having many members of the patients’ family present during deliveries and office visits (Leval, Widmark, Tishelman, & Ahlberg, 2010).

Perception on sexual health

HCP believe that women who have undergone FGM cannot experience sexual pleasure. They believe their sexuality has been taken from them and that FGM destroys the women’s sex life

“ *their sexuality is totally taken from them, too*”. They do not understand how women and men from cultures with FGM can physically have sex. They believe that men must be selfish aggressors and that sex must be forced and violent. The HCP even expressed believing sex must be like rape for these women. (Leval, Widmark, Tishelman, & Ahlberg, 2010).

“ I wonder how they get pregnant... How in the world can you get pregnant when I can't even get in a ...(holds up a finger)?” “Yeah right, a real man should be able to force his way in, with his machinery that is ”They (men) just get to take, they just take. Rape is the same thing there (Leval, Widmark, Tishelman, & Ahlberg, 2010).”

“It's so closely associated with sexuality and being female, as a woman it can like feel like a part of me is had been cut off...that your sexuality has been so completely altered (Leval, Widmark, Tishelman, & Ahlberg, 2010)”

“They can't possibly get any enjoyment from their sex life...” No , but they aren't meant to (Leval, Widmark, Tishelman, & Ahlberg, 2010).”

The HCP expressed wanting information and knowledge about the women with FGM sexual health but they felt they could never ask about it. They believe that finding answers to questions about sex and sexual health in regards to FGM is impossible and that the HCP lack of knowledge on the subject lead to their feelings of hatred not being alleviated (Leval, Widmark, Tishelman, & Ahlberg, 2010).

Method Discussion

Female genital mutilation is not yet well researched. The most researched area of FGM is childbirth and mortality. This subject area I wanted to avoid. I hoped that my result would show that FGM is a much broader subject matter that encompasses more than complications at childbirth. However it was difficult to find articles that met my aim and problem area. The same articles continued to be found after only a few searches. Even though the goal of my aim and problem area is not yet well researched I am satisfied that I have a recent result that is relevant to health care and health care professionals. I would have gotten a different result if I had only used articles from a nursing perspective. I believe that the result would have been biased and it would have had a focus on pregnant women and childbirth and the interesting result that women with FGM enjoy sexual satisfaction would have been lost. Also, using several HCP perspectives lead to the result showing that physical and medical complications are diverse and can be encountered even at a health clinic without specialized HCP. Finally, women with FGM are met in different areas of the health care system and because of this it was thought using different HCP perspectives could give a better understanding to how these women are treated in general.

I believe not using older articles that were referenced many times allowed a new result to come from that shows how little HCP have progressed in meeting and understanding women with FGM.

Some search terms are not presented in appendix IV because after analyzing the articles from those results the articles were not chosen. They did not meet the requirements for the aim or problem area of the literature study. Those search terms are sexuality and orgasm. However orgasm was taken up in other articles from other searches.

I also want to remark on the methods used in the articles on FGM: Several articles used the snowball technique to recruit participants. This can lead to bias. The nature of the subject matter is so sensitive that it is found to be the best technique to find willing participants (Lundberg & Gerezgiher, 2006) (Carroll, Epstein, Fiscella, Gipson, Volpe, & Jean-Pierre, 2007) (Berggren, Bergström, & Edberg, 2006).

Terminology used in questionnaires on sexuality is unlikely and unfamiliar for women from cultures that perform FGM. Only one article took this into consideration. The Female Sexual Function Index (FSFI) was made for western women and has not been adapted for women from other cultures. Control studies can only be done with women from western cultures because FGM is so widespread in the cultures with FGM (Catania, Abdulcadir, Puppo, Baldaro, Abdulcadir, & Abdulcadir, 2007).

There were low return rates in certain studies and this is believed to be because of the sensitive nature of the subject (Tamaddon, Johnsdotter, Liljestränd, & Essén, 2006).

Result Discussion

Physical Complications

Women with FGM have physical complications associated with the procedure. As a HCP it is important to think about this when diagnosing these women. Pain from menstruation could be , haematocolpos for example. It could be best to refer these women to specialist who have experience with the complications and with defibulation. Having knowledge on the different physical complications that can occur can decrease the amount of time a patient needs to suffer. I believe it would be best for Socialstyrelsen in Sweden to consult with specialist clinics around the world and provide guidelines on how to treat the complications and defibulation and refibulation issues with FGM. This would decrease the stress of the HCP and patients.

Defibulation/Refibulation

It is important that we use evidence based care in regards to defibulation and refibulation. Leaving the scar opened after delivery can cause severe pain and these women consider this “normal” anatomy to be an opened wound. They are unfamiliar with vaginal discharge and consider the new sensations as dirty. When it is best to be defibulated should also be researched. The women and the HCP are not in agreement on this area and this can cause mistrust and a negative health care experience. HCP lack of knowledge leads to more complications for these women. It is imperative in my opinion the HCP in Sweden are required in their general education to learn how to defibulate these women. This will provide a better experience of health care for both HCP and patients if the patients feel the HCP have

knowledge of what they are doing . The HCP will experience less stress and will no longer need to call several people from the health care team when they must defibulate.

Reinfibulation should be done with a patient centered care approach. If being defibulated is causing the women to experience psykological and medical complications then what the patient feels is best should be considered.

Communication

Communication between these women and HCP is also difficult and at times negative. Using interpreters that are trusted and female would contribute to better communication and remembering that women with FGM prefer to be cared for by women can lead to a more productive communication. The negative non-verbal communication from HCP is felt by the patients. This causes the patients to not want to come to appointments and they then do not receive the healthcare they should. It is important to ask the patients about FGM, they themselves will not bring up the issue due to the sensitivity of the subject but wish that HCP bring up the subject. I feel it would be best that specialized interpreters were used for these situations. If these women are met by the same interpreters in difficult situations they will build trust and less non-verbal communication will be needed. That will give the HCP a better understanding of the woman they are treating and decrease the misunderstandings' that occur.

Education/Knowledge

The women and the HCP who meet and care for these women agree that western health care professionals lack education and knowledge on the subject and culture of FGM. This leads to negative health care experience for both parties. HCP feel stress and the patients feel insecure. I strongly believe that HCP need a broader education. No patient starts in the health care system at a specialist clinic. This means that general education must include FGM. FGM is a part of western culture in the sense that with immigration and refugees we as HCP meet women who we are unfamiliar with culturally and medically.

Culture

Not understanding the culture of these immigrant patients causes false judgment and attitudes towards the patient and the patients' family. The HCP with non-verbal communication show their hatred for the culture and this can have a negative effect. The women may then demonstrate an over-identification with their own culture. This could lead to the patient continuing the practice on her own female children (Burke, 2011). Choi's theory of Cultural Marginality presented by Burke can lead to a better understanding of how two cultures can meet and have a productive and positive experience. This is achieved by understanding the different phases a women with FGM goes through in her transition into a new and unknown culture and how HCP can react in these different phases to not alienate the women but instead support her in her decision making process. It is also important to understand that my results show that FGM is a procedure with very old traditional roots and is decided on by older women in the community. It is the grandmothers and mothers that are deciding that these young girls will undergo FGM. These traditions are based on a belief that is passed down from generation to generation, each generation believing the older generation. Education is

the key to stopping this. This is not a tradition to please men sexually and men have very little to say about if it should happen or not. If we as HCP could better educate men on the difficulties and complications that FGM causes I believe we could help stop the tradition.

Health care experience

The experience is negative for both HCP and Patients. Patients describe feeling as if they are not trusted to make decisions themselves and that HCP make decisions for them. HCP describe feelings of needing to take care of the patients and protect them in a way they would not do for others. Neither the HCP or women with FGM describe positive health care experiences. It is possible that health care can be better achieved by using health care professionals from familiar cultures as liaisons between the two worlds. Women from countries that perform FGM have experience in dealing with other women with FGM. Many refugees have higher educations that are going to waste in western cultures because their educations are not “good enough” in the new country they move to. We need to go out into the community and learn from the experienced women and men who have worked as HCP in their home countries.

Sexual Health

It is a false assumption that these women lack or cannot have positive and healthy sexual experiences. The threat to female HCP own sexual health causes a barrier between themselves and the patient. Women who undergo defibulation by a specialist more than half of the time have an intact clitoris. This can lead to a new area of research on, how many clitorises are destroyed by unknowledgeable HCP who perform defibulation and assume the genitalia is already destroyed under the infibulated scar. It is also important to remember that sexuality, sexual health, orgasm, pleasure, desire and fantasy are not dependent on a clitoris. Important aspects of sexuality and sexual health are also emotions and other body parts.

Conclusion

Health care providers (HCP) and women with FGM, since the 1990's, have been encountering each other with little knowledge or trust of the situation causing a stressful and negative experience. These patients should be seen and met with patient centered care in focus. This will lead to the women with FGM being treated as whole person, remembering that they also have a sexual being and families. With education and knowledge on culture and FGM the health care experience can be improved for both the HCP and the patient.

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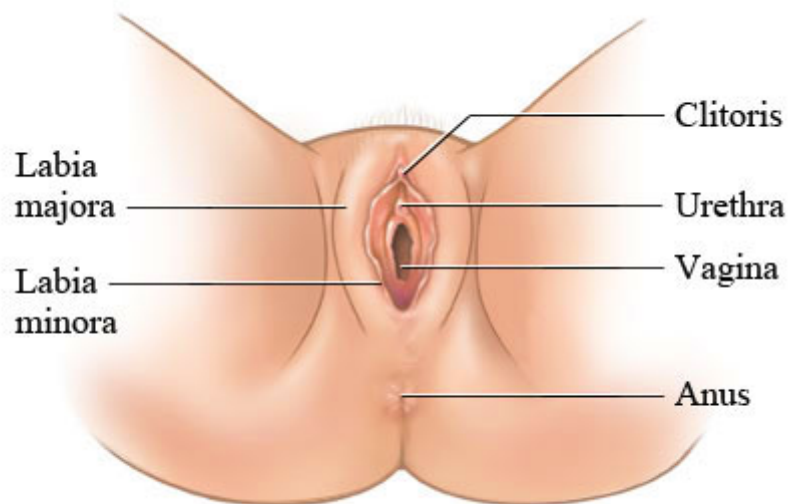
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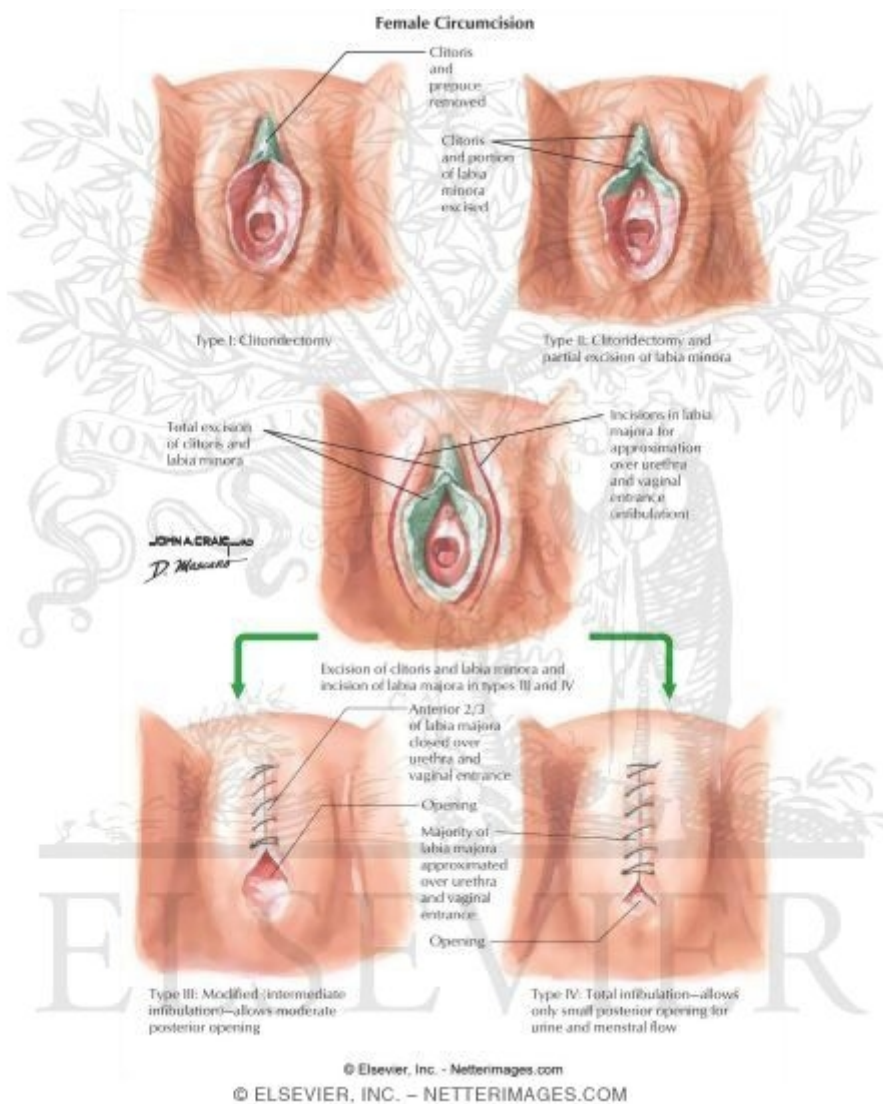
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Appendix I
Normal Female Genital Anatomy
(Sarah Anne Marshall, 2010)



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Appendix II
Types of Female Genital Mutilation
(Braddy & Files, 2007)



Appendix III

Percentage of girls and women age 15-49 who have undergone FGM by Country and region of Country and the Number of women born in those countries now living in Sweden. (Unicef; UNICEF, 2009) (Statistiska Central Byrån, 2013)

Country	% of girls and women living with FGM	Number of women born in said country living in Sweden
Djibouti	93%	125
Egypt	91%	1,720
Eritrea	89%	7,186
Guinea	96%	142
Mali	89%	50
Sierra Leone	88%	354
Somali	98%	21,729
Sudan	88%	1,107
Burkina Faso	76%	37
Ethiopia	74%	7,274
Gambia	76%	1,807
Liberia	66%	477
Mauritania	69%	9
Kurdish region of Iraq	51-80%	58,918*
Chad	44%	19
Ivory Coast	38%	370
Guinea Bissau	50%	50
Kenya	27%	1,708
Nigeria	27%	1,153
Senegal	26%	247
Benin	13%	24
Central African Republic	24%	45
United Republic of Tanzania	15%	795
Yemen	23%	429
Kurdish Region of Iraq	10-25%	58,918*
Cameroon	1%	467
Ghana	4%	947
Niger	2%	12
Togo	4%	146
Iraq	8%	58,918*
Uganda	1%	1,740

Appendix IV Data base search and chosen articles

Date	Data Base	Search Terms	Search Limits Used	Number of Results	Chosen Article		
Sept 30,2013	Scopus	"female genital mutilation" AND "nursing"	2000-Present Article	12	<table border="1"> <tr> <td>Referenced 13x</td> <td>Refereed yes</td> </tr> </table> <p>Experiences from pregnancy and childbirth related to female genital mutilation among Eritrean immigrant women in Sweden</p>	Referenced 13x	Refereed yes
Referenced 13x	Refereed yes						
Sept 30,2013	PubMed	"Female genital mutilation" AND "sexual health"	2000-2013	14	<table border="1"> <tr> <td>Referenced 30x</td> <td>Refereed Yes</td> </tr> </table> <p>Pleasure and orgasm in women with Female genital Mutilation/Cutting(FGM/C)</p>	Referenced 30x	Refereed Yes
Referenced 30x	Refereed Yes						
Sept 30,2013	PubMed	"nursing" "female genital mutilation"	2000-2013	31	<table border="1"> <tr> <td>Referenced 48x</td> <td>Refereed Yes</td> </tr> </table> <p>A study of Swedish midwives' encounters with infibulated African women in Sweden</p>	Referenced 48x	Refereed Yes
Referenced 48x	Refereed Yes						
Sept 30,2013	Cinahl	Female genital mutilation	2000-2013, Peer reviewed, Research article	40	<table border="1"> <tr> <td>Referenced 35x</td> <td>Refereed Yes</td> </tr> </table> <p>Female genital mutilation: analysis of the first twelve months of a southeast London specialist clinic</p>	Referenced 35x	Refereed Yes
Referenced 35x	Refereed Yes						
Sept 30,2013	Secondary search	Users that were interested in the article: A study of Swedish midwives' encounters with infibulated African women in Sweden		2	<table border="1"> <tr> <td>Referenced 31x, 14x</td> <td>Refereed yes, yes</td> </tr> </table> <p>Caring for Somali women: Implications for clinician-patient communication</p> <p>Being different and vulnerable: Experiences of Immigrant African Women who have been circumcised and sought maternity care in Sweden</p>	Referenced 31x, 14x	Refereed yes, yes
Referenced 31x, 14x	Refereed yes, yes						
Oct20,2013	Secondary search	Reference List of article: Pleasure and orgasm in women with Female genital Mutilation/Cutting(FGM/C)		2	<table border="1"> <tr> <td>Referenced 19x,8x</td> <td>Refereed yes, yes</td> </tr> </table> <p>Defibulation to treat female genital cutting: Effect on symptoms and sexual function</p> <p>The encounters that rupture the myth: contradictions in midwives' descriptions and explanations of circumcised women immigrants' sexuality</p>	Referenced 19x,8x	Refereed yes, yes
Referenced 19x,8x	Refereed yes, yes						
Oct20,2013	Secondary Search	Authors last name: Johnsdotter		1	<table border="1"> <tr> <td>Referenced 11x</td> <td>Refereed Yes</td> </tr> </table> <p>Swedish health care providers' Experience and knowledge of genital cutting</p>	Referenced 11x	Refereed Yes
Referenced 11x	Refereed Yes						
Sept 30, 2013	Secondary Search	Article From Study Protocol		1	<table border="1"> <tr> <td>Referenced 8x</td> <td>Refereed Yes</td> </tr> </table> <p>Perception of primary health professionals about Female Genital Mutilation: from healthcare to intercultural competence</p>	Referenced 8x	Refereed Yes
Referenced 8x	Refereed Yes						

AppendixV Article abstract

Authors: Pranee C. Lundberg PhD, RN; Alganesh Gerezgiher, BMSc,RN

Published Year: 2008

Title: Experiences from pregnancy and childbirth related to female genital mutilation among Eritrean immigrant women in Sweden

Journal: Midwifery

Land: Sweden

Aim: Increase the knowledge and understanding of midwives by exploring the experiences of women with FGM during pregnancy and childbirth

Method: Ethnographic Method of interviews which can generate knowledge about phenomena that is highly embedded within a culture, Snowball technique for participant selection, 15 Eritrean women participants, with interviews conducted in their home, with type III FGM, living in Sweden between 10-22years

Result: Six themes were discovered related to pregnancy and childbirth ; fear and anxiety, extreme pain and long term complications, HCP knowledge of circumcision and health-care system, support from family, relatives and friends, de-infibulation, decision against female circumcision for daughters

Authors: Jennifer Carroll, Ronald Epstein, Kevin Fiscella, Teresa Gipson, Ellen Volpe, Pascal Jean-Pierre

Published Year: 2007

Title: Caring for Somali Women: Implications for clinician-patient communication

Journal: Patient Education and Counseling

Land: USA

Aim: identify what Somali refugee women consider favorable communication and treatment in preventive healthcare service

Method: Qualitative in-depth interviews of 34 Somali women, conducted in a place convenient place for participants, who have been living in New York for between two months and nine years, Snowball technique for recruitment

Result: Prerequisites/foundations for favorable healthcare experiences were; easy access to healthcare system, continuity of care, attributes of patient-centered communication, feeling valued and respected as a person. Clinician factors related to respectful treatment were; availability of female clinician and female interpreter, gynecologic concerns(circumcision) and need for privacy, need for Somali health care workers and health education programs

Authors: Vanja Berggren, Staffan Bergström, Ann-Karin Edberg

Published Year: 2006

Title: Being Different and Vulnerable: Experiences of immigrant African women who have been circumcised and sought maternity care in Sweden

Journal: Journal of Transcultural Nursing

Land: Sweden

Aim: Explore the experiences of Women from Africa with FGM in regards to Swedish maternity care

Method: 21 explorative interviews, conducted in the participants homes, of women living In Sweden from Africa with FGM. Snowball technique for recruitment of participants

Result: Three main themes with seven sub themes were discovered: 1) suffering from being abandoned and mutilated, being an infant victim, suffering as women 2) Being exposed in the encounter with the Swedish HCP, being in the hands of others, being stared at, being looked down on 3) Trying to adapt to a new cultural context, missing the female community, striving for the protection of own daughters

Authors: Lucrezia Catania MD, Omar Abdulcadir MD, Vincenzo Puppo MD, Jole Baldaro Verde PhD, Jasmine Abdulcadir, Dalmar Abdulcadir

Published Year: 2007

Title: Pleasure and Orgasm in Women with female genital mutilation/cutting (FGM/C)

Journal: Journal of Sexual Medicine

Land: Italy

Aim: To analyze four investigations on sexual function in different groups of women with FGM

Method: Semi structured interviews and the Female Sexual Function Index (FSFI)

Result: infibulated women compared to control group of women without FGM scored significantly higher in several domains of sexual function. Women with FGM (all Types) can have an orgasm

Authors: Nawal M. Nour; MD ,MPH, Karin B. Michels; ScD, MSc, Anne E. Bryant; MD,MPH

Published Year: 2006

Title: Defibulation to treat female genital cutting

Journal: American College of Obstetricians and Gynecologists

Land: USA

Aim: To discover the effect of difibulation for the woman and her partner on physical complications and sexual function

Method: Medical record review and post- procedure surveys of forty women

Result: Defibulation leads to alleviation of long term physical complications of FGM and a better sexual satisfaction for women and their partner

Authors: Catarina Widmark RN, RM , Carol Tishelman RN and Dr of MedSCI, Beth Maina Ahlberg PhD

Published Year: 2002

Title: A study of Swedish midwives' encounters with infibulated African women in Sweden

Journal: Midwifery

Land: Sweden

Aim: Determine Swedish midwives' perceptions and attitudes towards FGM, their experiences of caring for these women and the training the midwives have received for caring for women with FGM

Method: a multi-stage sampling procedure to identify midwives who had delivered women with FGM, an open ended questionnaire was used to select 26 midwives working in maternity wards and prenatal clinics to participate in the in depth interviews and focus groups of the study

Result: Three themes were discovered; emotions and communicational challenges, knowledge and skills needed for caring for these women and reliance on Swedish law when dealing with dilemmas with dealing with women with FGM and their families

Authors: Amy Leval BA, Catarina Widmark RN, RM, Carol Tishelman RN and Dr of MedSCI, Beth Maina Ahlberg Phd

Published Year: 2010

Title: The encounters that rupture the myth: Contradictions in midwives' descriptions and explanations of circumcised women immigrants' sexuality

Journal: Health Care for Women International

Land: Sweden

Aim: investigate midwives views of sexuality in the context of caring for women with FGM

Method: Analytical expansion of data of the study: A study of Swedish midwives' encounters with infibulated African women in Sweden(authors; Catarina Widmark, Carol Tishelman, Beth Maina Ahlberg)

Result: Four major themes were discovered; ethnocentric projections of sexuality, a paradoxical relationship to knowledge concerning circumcision and sexuality(they do not seek answers to their questions), women with FGM are seen as powerless in relation to society and male dominance, maternity wards and prenatal clinics are where gender and culture meet allowing masculine norms to be ruptured

Authors: Leila Tamaddon, Sarah Johnsdotter, Jerker Liljestrand, Birgitta Essén

Published Year: 2005

Title: Swedish health care providers' experience and knowledge of Female Genital Cutting

Journal: Health Care for Women International

Land: Sweden

Aim: evaluate the experiences and knowledge of health care providers in Sweden in regards to FGM

Method: analysis of quantitative, structured questionnaires from gynecologists, pediatricians and midwives in Sweden

Result: HCP are meeting women with FGM who suffer from long term complications from FGM and have also suspected new cases of FGM, HCP lack guidelines on how to care for women with FGM and their self- estimation of having adequate knowledge on FGM

Authors: Adriana Kaplan-Marcusan, Pere Toran- Monserrat, Juana Moreno-Navarro, Ma Jose Castany Fabregas, Laura Munoz-Ortiz

Published Year: 2009

Title: Perception of Primary health professionals about Female Genital Mutilation: from healthcare to intercultural competence

Journal: BMC Health Services Research

Land: Spain

Aim: analysis of perceptions, degree of knowledge, attitudes and practices of HCP in relation to FGM

Method: quantitative cross-sectional study between 2001 and 2004 analysing self-administered questionnaires of family/general physicians, pediatricians, nurses, midwives, gynecologists

Result: statistically significant differences on: number of FGM patients treated, HCP do not have adequate knowledge on FGM, HCP have begun to receive training on FGM and their attitudes on dealing with FGM are changing

Authors: Comfort Momoh, Shamez Ladhani, Denise P. Lochrie, Janice Rymer

Published Year: 2001

Title: Female Genital Mutilation: analysis of the first twelve months of a southeast London specialist clinic

Journal: British Journal of Obstetrics and Gynaecology

Land: Great Britain

Aim: analysis of sources and reasons for referral to a new specialist clinic for women with FGM, and to determine the consequences of FGM

Method: retrospective descriptive case study of one hundred and sixteen women over one year

Result: women with FGM are in need of care for physical complications of FGM, doctors and midwives need to specifically enquire on FGM when caring for women from high risk countries, reinfibulation is not requested after delivery even when offered, women's physical complications do not lead to them abandoning the tradition in relation to their own daughters