

SERVICES FOR WOMEN WITH FEMALE GENITAL MUTILATION IN CHRISTCHURCH: PERSPECTIVES OF
WOMEN AND THEIR HEALTH PROVIDERS

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Abstract

In recent decades there has been increased immigration to New Zealand of women from East Africa. These countries have the highest prevalence rates (between 90-97%) of Female Genital Mutilation (FGM) worldwide. FGM therefore has become part of the care experience of some New Zealand health providers. Information on FGM is available on the New Zealand Ministry of Health website.

This study captures the experience of a group of East African women in Christchurch who have undergone FGM and given birth in Christchurch Hospitals. Two focus groups, each with ten women, were held so that women could talk about their health services experience. A narrative approach was adopted, listening to their stories in order to explore, to gain insight and to understand how these women felt during reproductive and antenatal care, childbirth and after childbirth. Interviews with three health providers sought their experiences of caring for women with FGM.

The study identifies diverse potential explanations with the focus group members telling their stories and identifying issues related to FGM. Several short case histories are presented to illustrate these experiences. The thematic analysis reported four themes: satisfaction with clinical care, concern about infibulation, barriers to knowledge for women, and problems of cross-cultural communication. Health providers reported similar issues, with themes related to their own clinical experience, knowledge gaps, and need for greater cultural understanding and communication. These themes reflect the journey of the East African women with FGM in Christchurch and the challenges faced by them and their providers.

This research recommends that women with FGM receive more education and support to manage their relationships with the health system and their own health. Health providers need continuing education and further support in the psychosocial, psychological and physical health needs of East African women living in Christchurch. Service outcomes should be evaluated.

Keywords: Circumcision; Female; Female Genital Mutilation (FGM)

Glossary

Adnexa of the uterus	The adnexa of the uterus refers to the structures most closely related structurally and functionally to the womb.
Anaemia	A condition where the blood has reduced ability to carry oxygen. This causes headaches, tiredness and lethargy at a minimum. Breathlessness, dizziness and heart pains accompany greater reductions in blood oxygen levels.
Anal sphincter	Ring of muscle in the anus controlling the exit of faeces.
Anorgasmia	An inability to achieve orgasm.
Apgar scores	Apgar is an acronym for the five indicators of new-born health i.e., A ctivity (muscle tone), P ulse, G rimace (reflex irritability), A ppearance (skin colour) and R espiration.
Atrophic vaginitis	Inflammation of the vagina, caused by the lack of oestrogen, usually found in women who have gone through the menopause.
Caesarean section (C section)	This is an operation to deliver a baby through a cut in the abdomen, often to save the life of both mother and baby.
Candida	A vaginal fungus causing an inflammatory infection.
Case-control study	Such studies involve identifying patients who have the outcome of interest (cases) and control patients without the same outcome, and looking to see if they had the exposure of interest.
Case-series	A report on a series of patients with a common outcome of interest. No control group is involved.
Case study (or case report)	In social/life sciences a case study is a descriptive, exploratory or explanatory analysis of a person, group or event. An explanatory case study can explore causation in order to find underlying principles. Case studies may be <i>prospective</i> (in which criteria are established and cases fitting the criteria are included as they become available) or <i>retrospective</i> (in which criteria are established for selecting cases from historical records for inclusion in the study).

Catheter	A tube used to drain excess fluid e.g. urinary fluid from the bladder when the bladder is blocked.
CDC	Centers for Disease Control (Atlanta, Georgia, USA).
Cervicitis	Inflammation of the cervix.
Cervix	The neck of the womb, located at the top of the vagina.
Chi-squared analysis	Chi-square is a statistical test commonly used to compare observed data with data we would expect to obtain according to a specific hypothesis.
CRS	Christchurch Resettlement Services.
Chlamydia	A micro-organism causing vaginal infections.
Clavicle	Collar bone.
Clitoris	A small sensitive and erectile organ in the female genitals located under the labia minor (see below).
Clitoridectomy	Removal of the clitoris.
Cross sectional studies	Also known as cross-sectional analyses, transversal studies, prevalence study) are a type of descriptive <i>observational study</i> that involves data collection from a population, or a representative subset, <i>at one specific point in time</i> . They differ from <i>case-control studies</i> in that they aim to provide data on the entire population under study. Case-control studies typically include only individuals with a specific characteristic, with a sample, often a tiny minority, of the rest of the population.
De-infibulation	A surgical technique to reverse the closure of the vaginal opening after a type III infibulation, and consists of a vertical cut opening up normal access to the vagina.
Dilatation and curettage (D&C)	Scraping away the lining of the womb to ensure the womb is empty after a miscarriage.
Dysmenorrhea	Pain or discomfort suffered by a female just before or during a menstrual period.
Dyspareunia	Painful sexual intercourse
Dyspnoea	Difficulty in breathing, breathlessness.
ECG	Electrocardiogram, a measurement of the variation of the electrical impulses in heart muscle as it beats.

Ectopic pregnancy	A pregnancy occurring in one of the fallopian tubes that lead from the ovaries to the uterus (womb). The pregnancy can sometimes occur in the ovary. The most likely cause is damage to the fallopian tubes causing the fertilised egg to stick in the tube.
Endometrial	Of the cells lining the womb.
Endometritis	Inflammation present in the lining tissues of the womb.
Episiotomy	A cut made in the genital tissues (perineum) to enlarge the vaginal opening. These cuts usually occur when labour is making slow progress or if forceps are necessary to deliver the baby. Anterior cuts are made at the front of the genitals and medio-lateral cuts are made across the middle of the genitals.
Ergometrine	A drug used to contract the womb and control excessive bleeding from the womb after childbirth.
Fallopian tube	This stretches between the ovaries and the womb. The male sperm fertilises the female's egg here.
Femur	The thighbone.
Female Circumcision	Also called female genital mutilation (FGM) (see below). FGM is the preferred term because it more accurately depicts what women have experienced. In contrast female circumcision implies that the procedure is the equivalent of male circumcision.
FGM	<p>Female genital mutilation. FGM is the cutting of the clitoris of girls in order to curb their sexual desire and preserve their sexual value before marriage. A number of East African countries practise this, but there are other countries with this practice. There are 4 types of FGM:</p> <ul style="list-style-type: none"> • type I: Removal of the hood of the clitoris only. • type II: Removal of both the hood and clitoris plus partial or total removal of the small lips surrounding the clitoris. • type III: stitching/narrowing of the vaginal opening (infibulation). • type IV: Unclassified: Pricking, piercing, or incision of the clitoris and/or labia, stretching of the clitoris and/or labia.

Gastro-intestinal	The digestive system.
Gestational diabetes	A medical condition that affects 3%-10% pregnancies, whereby a pregnant woman who, prior to pregnancy, was not diabetic, develops diabetic symptoms (high blood glucose levels).
Gynaecology	Gynaecology is the medical specialty concerned with the female reproductive tract.
GP	General practitioner (doctor).
Haemorrhage	Excessive bleeding.
Hematocolpos	A medical condition whereby the vagina fills with menstrual blood. In the instance of FGM it is as a consequence of an insufficiently sized vaginal passage for the normal discharge of blood.
Herpes virus (HSV2)	<i>Herpes simplex virus type 2</i> . A contagious disease producing numerous painful blisters on the genitals. Babies can acquire the infection during birth.
Histological analysis	An analysis of the minute structures of the tissues.
Human immuno-deficiency virus (HIV)	A type of virus that causes AIDS (Acquired Immuno-deficiency syndrome).
Hypertensive disorder	Raised blood pressure.
Infibulation	Removal of all or part the outer lips surrounding the vagina and stitching/narrowing of the vaginal opening.
IUD/ IUCD	Intra-uterine device, the device is inserted in the womb and prevents pregnancy occurring. Sometimes IUCD (intra-uterine contraceptive device) is used instead.
IVF	<i>In vitro</i> fertilisation. A male sperm fertilises a female egg under laboratory conditions. This fertilised egg is then implanted inside a woman wishing to have children.
Keloid scars	A raised, hard, irregularly shaped and itchy scar on the skin.
Labia major	Outer lips of a woman's genitals covering the vagina.
Labia minor	Inner lips of a woman's genitals covering the clitoris.
Labial adhesions	The lips of the female genitals stuck together by an infection.
Laparoscopy	A technique where view the contents of the abdomen through an endoscope (tube-like instrument with a viewing lens and light)

	inserted in an incision near the umbilicus (belly button).
Lower ileum	The final portion of the small intestine.
Neisseria gonorrhoea	A bacterium causing disease of the genital tract and some other organs transmitted by sexual activity or during the birth process in the case of gonococcal eye disease in babies.
Neonate	A new-born baby.
Neurogenic shock	A life-threatening medical condition in which there is insufficient blood flow throughout the body.
Non-specific vaginitis	An inflammation of the vagina caused by its own bacteria.
Observational study	A study in which a researcher simply observes behaviour in a systematic manner, there is no attempt to influence or interfere with the behaviour.
Obstetrics	Obstetrics the medical specialty concerned with the pregnancy, childbirth and postpartum care of women.
Pelvic inflammatory disease (PID)	PID is an infection of the internal female reproductive organs.
Perineum	The tissues between bowel opening at the back and the genitals at the front of the body. In women, this area can be cut during birth to enlarge the vaginal opening and make childbirth easier for the baby. (See episiotomy above).
Peritonitis	Inflammation of the peritoneum, the membrane that lines the abdominal cavity and covers most of the abdominal organs.
Postpartum	The period immediately following childbirth.
Post-traumatic stress disorder	A specific form of anxiety brought on by a stressful or frightening event. Common causes include natural disasters (e.g. earthquakes), violence, rape, torture and serious physical injury.
Pre-eclampsia (previously referred to as toxemia)	A potentially life-threatening medical condition affecting 2%-8% of pregnancies, characterised by high blood pressure and significant amounts of proteinuria (see below). Treatment is delivery of the foetus and placenta.
Proteinuria	The urine contains proteins, indicating possible heart or kidney disease.
Puerperal	Relating to or occurring in childbirth or immediately after.

Rectum	The final part of the colon, connected to the anus.
Reflux	An abnormal backflow of body fluids in a bodily passage. This occurs when the exit of the passage does not close properly.
Salpingitis	Inflammation of the fallopian tubes.
Sigmoid colon	This is the lower part of the colon leading directly to the rectum.
STI	Sexually transmitted infection.
Student's T-test	A t-test's statistical significance indicates whether or not the difference between two groups' averages most likely reflects a "real" difference in the population from which the groups were sampled.
Trichomoniasis	This is a parasite causing a vaginal infection.
UN	United Nations.
UNFPA	United Nations Population Fund, formerly the United Nations Fund for Population Activities.
UNICEF	United Nations International Children's Emergency Fund.
Ureter	One of two tubes carrying urine from the kidneys to the bladder.
Urethra	The tube by which urine is excreted from the bladder.
Urethral (urinary) catheterisation)	The insertion of a tube to drain urine from the bladder.
Urinary retention	The bladder cannot empty fully or in part because of a blockage. If the bladder is always full, urine dribbles out constantly. Backpressure from the condition may lead to kidney damage.
Urogenital tract	Comprises all the organs and passageways of the urinary and genital systems.
Urinary incontinence	The uncontrollable passing of urine.
Uterine atony	Poor muscle tone in the womb.
Uterus	The womb.
UTI	Urinary tract infection.
Vaginal fistulae	An abnormal passage through to the bladder or the anal sphincter caused by injuries received during childbirth.
Vulva	The external, visible part of female genitals.
WHO	World Health Organisation.

Chapter 1: Introduction

"There is no single practice which has such dramatic negative effect on health in the broadest sense as Female Genital Mutilation." (Dr Mark Besley, 1992, cited in Dorkenoo, 1994: 13).

1 Approach and purpose of this thesis

This thesis investigates the impact of female genital mutilation (FGM) on the health and well-being of migrant women in Christchurch. The World Health Organization (WHO, 1996) defines FGM as the partial or total removal of the female external genitalia and/or injury to the female genital organs for cultural or any other non-therapeutic reasons.

The anatomy and processes of female gynaecology and reproduction are discussed in relation to FGM. Most of the relevant medical terminology is in general use in the community and well understood by an educated reader. When other technical terms are used where possible they are explained at the time and reported in "plain English". In addition a glossary is included to assist the reader.

1.1 Definition of female genital mutilation

FGM is the cutting of the clitoris of girls in order to curb their sexual desire and preserve their sexual value before marriage (UNICEF, 2005; McCloud 2003). There are four broad types of FGM defined by WHO (1996):

type I	Circumcision: consists of the removal of the prepuce or hood of the clitoris only.
type II	Excision of the prepuce and clitoris together with partial or total excision of the labia minor.
type III	Excision of part or all of the external genitalia and stitching/narrowing of the vaginal opening (infibulation).
type IV	Unclassified: Pricking, piercing, or incision of the clitoris and/or labia, stretching of the clitoris and/or labia.

The closure of the vaginal opening via FGM is known as infibulation. De-infibulation is a surgical technique to reverse the closure of the vaginal opening after a type III infibulation, and consists of a vertical cut opening up normal access to the vagina.

Even though presentations of FGM differ from country to country, FGM is usually done in girls less than 10 years old and leads to scarring in the vulval area. The presence of this scar tissue, which is less elastic than the perineal and vaginal tissue, causes differing degrees of obstruction and tears, often necessitating an episiotomy during childbirth (Shandall, 1967).

1.2 History and Practice of Female Genital Mutilation (FGM)

FGM has been practised for more than 5,000 years with some Egyptian mummies identified as having had the procedure (Elchalal et al., 1997; El Dareer, 1983a; 1983b). Historically, many cultures practising FGM have believed that women are predisposed to promiscuous behaviour (Muteshi and Sass, 2005). This is a particularly undesirable trait in cultures where a woman's virginity and fidelity are closely associated with parental and familial "honour" (Yuval-Davis, 1997).

FGM is considered an integral part of a girl's social development and is believed to be normal in communities where it is practised. Women fear that they will not find husbands for their daughters if the daughters have not been mutilated and these women believe that men prefer sex with a mutilated wife. In addition, the clitoris is thought to be the "masculine" part of the female genitalia, and there is a fear that it has the potential to grow as big and long as a male penis (Lightfoot-Klein, 1989b). Removal of the clitoris therefore reflects a social construct of female aesthetic beauty affirming women's femininity. Europe too had a history of controlling women's sexuality through FGM; for example, female slaves in ancient Rome were forced to wear rings threaded through their labia to prevent them from becoming

pregnant, and clitoridectomy was the surgical "remedy" for masturbation in Victorian England and in the United States (Assaad, 1980; Wallerstein, 1980).

Genital mutilation was initially practised on female slaves to minimise their sexual pleasure and was intended to keep slaves from getting pregnant thus maximising their labour and efficiency (Lightfoot-Klein, 1989a). Following the Geneva Convention in 1952, New Zealand and other parts of the western world have become home to refugee immigrants that include many women with FGM. These migrants have dual identities and consider themselves New Zealanders (or Australian, or European etc.) yet cannot truly be deemed such due to the influences of their former cultural practices such as FGM. These practices still influence their newfound culture. In western society, genital mutilation is considered barbaric and cruel to those affected by it; however, there are historical and social contexts that need to be understood.

Traditions constitute learned habits passed from generation to generation and are often guided by taboos and this makes traditions very difficult to change. People adhere to these patterns of behaviour, believing that this is "the right way". Most women from cultures practising FGM refer to the practice as both a tradition and a religious obligation. When asked why they subject their daughters to the FGM operation, many women respond, "it has always been like that," with the clitoris considered "dirty". Assaad (1979) reports that Muslims and academics in the West are at pains to insist that the practice is not rooted in the Islamic religion but rather in culture. Given that in Saudi Arabia, a Muslim country, FGM is not only not practised but it is also condemned it becomes clear that it is a false notion that it is an Islamic practice.

Refugee and migrant families bring many traditional practices from their homeland and from their different ethnic and cultural groups, including Christians, Muslims, Jews, and followers of indigenous African religions (Verzin, 1975).

1.3 FGM procedure and its consequences

The age at which girls undergo FGM varies, depending on their ethnic group or geographical location. The timing of the FGM procedure is often flexible even within communities. The procedure may be carried out on infant girls, during childhood or adolescence, at the time of marriage, at a woman's first pregnancy, or during labour. In some communities and in rural areas, surgery is done without anaesthesia, so there is high risk of disease and infection. The surgery involves either partial cuts to the labia major, labia minor, and clitoris or even their complete removal and the wounds then stitched together. The young girls are physically restrained and remain conscious throughout the operation. At the end of operation the girl's legs are tied together for several days or weeks to make sure that the wound heals well, a small opening like a pinhole is left to allow urine to escape. Menstrual blood flows through the same small opening once a girl reaches puberty. A small opening may result in dysmenorrhea and hematocolpos (painful retention and accumulation of blood in the vagina) (Agugua and Egwuatu 1982).

FGM practices have negative effects on female health and violate human rights as well, denying female sexuality. The meaning of FGM is embedded in localised historical, social and cultural practices and because of the multitude of culturally specific meanings attached to its continuance; its eradication often poses complex challenges and requires a prolonged multifaceted effort (Gruenbaum, 2006).

1.4 Prevalence of FGM

According to the World Health Organization, 100–140 million women and girls worldwide are living with FGM, and an estimated three million girls are subject to this procedure every year (WHO, 2008). The practice persists in 28 African countries across Asia and the Middle East. Abbas also calculates that 100,000 women and teenagers die from complications related to FGM in childbirth per annum (Abbas, 2006). The prevalence of FGM varies widely from country to country. FGM ranges from “nearly 90% or higher in Egypt, Eritrea, Mali, Sudan, and Somalia, to less than 50% in the Central African Republic and Cote d’Ivoire, and 5% in the Democratic Republic of Congo and Uganda” (Rahman and Toubia, 2000). See Table 1 for further detail.

There are currently thousands of African women with FGM who have settled in New Zealand and other western countries who have brought many traditional practices from their homeland and their ethnic and cultural groups (Verzin, 1975).

Table 1. African Countries With The Highest FGM Prevalence Rates.

	Country	Source	Year	Estimated % prevalence of FGM in girls and women 15-49 years
1	Somalia	MICS	2006	97.9
2	Egypt	DHS	2005	95.8
3	Guinea	DHS	2005	95.6
4	Sierra Leone	MICS	2005	94.0
5	Djibouti	MICS	2006	93.1
6	Sudan	Local Survey	2006	89.3
7	Eritrea	DHS	2002	88.7
8	Mali	DHS	2006	85.2
9	Gambia	MICS	2005-2006	78.3
10	Ethiopia	DHS	2005	74.3
11	Burkina Faso	MICS	2006	72.5
12	Mauritania	MICS	2007	72.2
13	Liberia	DHS	2007	58.3
14	Chad	DHS	2004	44.9
15	Guinea-Bissau	MICS	2006	44.5
16	Ivory Coast	MICS	2006	36.4
17	Kenya	DHS	2003	32.2
18	Senegal	DHS	2005	28.2
19	Central African Republic	MICS	2006	25.7
20	Yemen	DHS	1997	22.6
21	Nigeria	DHS	2003	19.0
22	Tanzania	DHS	2004-2005	14.6
23	Benin	DHS	2006	12.9
24	Togo	MICS	2006	5.8
25	Ghana	MICS	2006	3.8
26	Niger	DHS	2006	2.2
27	Cameroon	DHS	2004	1.4
28	Zambia	Local Survey	2005	0.9
29	Uganda	DHS	2006	0.6

(NB: This is the most recent analysis as data are difficult to compile as FGM is illegal in many countries)

Key: MICS = Multiple indicator cluster surveys

DHS = Demographic health survey

Source: http://www.blatantworld.com/feature/africa/female_genital_mutilation.html

1.5 East African Women in New Zealand

In New Zealand, the main ethnic groups affected by FGM are the Somali, Ethiopian, Egyptian, Eritrean and Sudanese communities. International reports indicate that FGM is practised in parts of Malaysia, Indonesia and India, so there is the possibility that some females from these communities and living in New Zealand had FGM in their homeland.

As noted in Table 1 above there is no precise information on the number of women affected by FGM in those countries from which New Zealand's refugees and immigrants are drawn. While there is no documented information that FGM is being practised in New Zealand there is a growing number of refugees and migrants from those countries where FGM is practised and therefore in all probability there are a growing number of women who have previously undergone FGM.

In January 1996, the New Zealand Government made the practice of FGM illegal under an amendment to the Crimes Act (section 204A) 1961 because the New Zealand Government believes that it is harmful to the health of women and girls. The Act states that it is illegal to perform "any medical or surgical procedure or mutilation of the vagina or clitoris of any person..." for reasons of "...culture, religion, custom or practice". If someone performs FGM, he/she is breaking the law and faces up to seven years imprisonment. The punishment occurs whether the person performs the procedure, assists in the procedure, or gets someone else to perform FGM.

New Zealand is also a signatory to the following International Instruments and conventions that encourage and oblige action against the practices of FGM:

1. The Universal Declaration of Human Rights (Article 25).
2. The Convention on the Elimination of all Forms of Discrimination against Women (Articles 2f, 5a, 12).
3. The Convention on the Rights of the Child (Articles 2, 19.2, 24.1, 37a, 24.3).

1.6 Research aims and objectives

The overall purpose of this research is to understand the situation of both the Christchurch women with FGM and their health providers, in order to increase knowledge of FGM and ensure improved health services for women with this condition.

1.6.1 Specific research questions:

- 1) How do women who have undergone FGM experience health services and have their needs met?
- 2) What is the experience of health providers who care for African women who have undergone FGM, and what do they need to improve their knowledge and practice?

1.6.2 Two part research investigation:

- 1) Two focus group discussions with East African women in Christchurch who have undergone FGM.
- 2) Semi-structured interviews with a sample of providers providing care to women with FGM.

1.7 Structure of the thesis

A literature review in Chapter Two considers the way in which FGM affects the health and well-being of women through their lives. The immediate health complications of FGM in the

early years of life, the long term health complications of FGM, including its impact on the reproductive system are discussed as well as the consequences of FGM (such as infections and anatomical damage). Adverse obstetric outcomes are also considered. The psychological impacts of FGM, psychosomatic problems, de-infibulation and implications for healthcare professionals are examined.

Chapter Three describes qualitative research as a method of social inquiry that emphasises the way people understand and make sense of their experiences and the environment. This methodology is suited for use with marginalised populations like refugees and migrants, particularly because of the ethical issues involved.

The result of the focus groups and the semi-structured interviews with health providers are presented in Chapter Four and the implications of the findings are examined in Chapter Five.

Chapter 2: The Health Implications of Female Genital Mutilation

2 Introduction

This literature review considers the way in which female genital mutilation (FGM) affects the health and well-being of women throughout their lives.

2.1 Description of search processes, dates and keywords

A difficulty in searching the literature is that "female circumcision" has only become a "keyword" in the last two decades (WHO, 2002). Articles identified in the computer search pointed to key journals, which have published studies on the topic of FGM. Those journals that included articles on the health complications of FGM were then manually searched from the start of the journal's publication until the time they became part of a computerised database when a computer search became possible. In addition, those journals were searched that have, or have had, a geographical focus on the parts of Africa where FGM is widely practised and where at least one article on the health complications of FGM was identified.

There is a hierarchy of evidence to consider. Cross sectional studies of outcome, case series, observational studies, case reports, and anecdotes from personal observation provided the best evidence. Cross sectional interview studies and personal reports from women with FGM who have experienced complications were considered next. These studies also recognised that the degree of severity of FGM and number of times that women give birth influences the obstetric outcome.

Smaller studies have suggested that adverse obstetric outcomes such as episiotomy, tears, protracted labour, postpartum haemorrhage and low Apgar scores (an objective score of the condition of a baby after birth) might be more common in deliveries in women with genital mutilations. However, consistent data about the effects of FGM by type were not available.

Reliable studies using specific obstetric outcomes were limited, many had inconsistent findings and they seldom accounted for potential confounding factors. In addition, many failed to investigate the effects of different types of FGM and relied on self-reporting of obstetric complications. Many early studies also had insufficient power to test essential outcomes e.g., stillbirth and early neonatal death.

Case studies, case report studies or case series produce much more detailed information than is usually available through a statistical analysis. However, it may be difficult to generalise from these because of inherent subjectivity. In addition, because they are based on qualitative subjective data they may be generalisable only to a particular context (Hakin, 2001; De Silva, 1989; Jones et al., 1999). Most of the case studies found were reported in medical journals from Kenya, Sudan, Nigeria, Gambia and West Africa.

2.2 Immediate Health Complications of FGM in early of life

There are a number of immediate complications of FGM, including excessive bleeding, pain and shock, urinary retention, infections and fractures.

Excessive bleeding is one of the most common immediate complications of FGM because excision of the clitoris involves cutting across the high pressure clitoral artery and attempts to stop the bleeding may not be effective. Sometimes haemorrhage occurs in the first week after infibulation because the clot over the artery sloughs off, often because of infection. This has been noted in both FGM types I and II (El-Defrawi et al., 2001; Dare et al., 2004; Malmström, 2007) and in FGM type III (Boddy, 1989; Dirie and Lindmark, 1992; Chalmers and Hashi, 2000).

Shock may occur because of blood loss and the severe pain and trauma of the procedure. Both excessive bleeding and neurogenic shock (a life-threatening medical condition in which

there is insufficient blood flow throughout the body) can be fatal. This has been specifically noted for both FGM Types I and II (Egwuatu and Agugua, 1981; Agugua and Egwuatu, 1982) and FGM type III (Dirie and Lindmark, 1992; Almroth et al., 2005a).

The majority of FGM procedures are performed without anaesthetics and cause the girl severe pain. Even if a local anaesthetic is used, multiple insertions of the needle are often required. Agonizing pain due to lack of anaesthesia has been reported in FGM Types I and II by El-Defrawi et al., (2001), Dare et al., (2004), Dirie and Lindmark (1992), Chalmers and Hashi (2000), Gruenbaum (2001) Johansen (2002) and Almroth et al., (2005a).

Urinary retention is very common following FGM and may last for hours or days and is a result of swollen tissues, inflammation, damage to the urethra and its surrounding tissue, labial adhesion or near complete closure of the vaginal orifice. Girls may also fear passing urine because of the pain and burning sensation of urine on the raw wound. Pain from passing faeces is also common (El-Defrawi et al., 2001; Dare et al., 2004; Yoder et al., 2004).

Infections may spread after repeated use of the same instruments without sterilization for FGM surgery procedures. Injury to the urethra, vagina, perineum and rectum can result from the procedures conducted in poor light or from careless techniques. Healing practices, such as binding of the legs following infibulation, prevent wound drainage (Dirie and Lindmark, 1992; Chalmers and Hashi, 2000; Almroth et al., 2005a, 2005b).

Fracture or dislocation of the clavicle, femur, or hip joint can occur because heavy pressure is applied to a struggling girl during the FGM procedure when several adults hold the girl down (Dirie and Lindmark, 1992; Chalmers and Hashi, 2000). Wounds may fail to heal because of infection, urine flowing over the raw wound, and underlying anaemia of the often malnourished girls. Repeated female genital mutilation appears to be quite frequent in type III

FGM and is usually due to unsuccessful healing (Dirie and Lindmark, 1992; Chalmers and Hashi, 2000).

2.3 Long term health complications of FGM

2.3.1 Urinary tract infection (UTI)

The urinary tract is the body's drainage system for removing wastes and extra water; it is composed of two kidneys, two ureters, a bladder and urethra. The kidneys, (a pair of bean-shaped organs size of a fist), are located below the ribs toward the middle of the back with one on each side of the spine. The kidneys filter the blood, draining away wastes and extra water. Two narrow tubes (ureters) carry urine from the kidneys down to the bladder, where it is stored and emptied through the urethra (a tube at the base of the bladder opening to the outside of the body). In females, the bladder lies directly behind the pubic bone and in front of the vagina. The exterior opening of the urethra lies between the clitoris and vaginal opening.

Structural abnormality urinary tract infection resulting from FGM can predispose a girl to recurrent urinary tract infections. This occurs when a flap of skin obstructs the urethral channel after infibulations, and urine does not jet out during urination. Infibulation scars may block the urethral orifice, which leads to the accumulation of urine. The scarring not only affects the flow of urine, but also the passing of menstrual blood. This permits the entry of bacteria into the urinary tract increasing the risk of recurrent urinary tract infections (UTI) and possible reflux of urine into the bladder and kidneys (Dirie and Lindmark, 1992). Girls who have undergone FGM may report a slow urinary stream, straining and urine retention (Nour, 2004). A study from Sudan showed that for girls under the age of seven there was a significant association between FGM and suspected urinary tract infection, and that symptoms from the urogenital tract in girls were heavily under-reported (Almroth, 2005a).

Labial adhesions (i.e. where the labia stick together because of infection) and urethral stricture are known risk factors of recurrent UTI. Recurrent UTI in girls is associated with renal damage (Saadeh and Mattoo, 2011).

2.3.2 The reproductive system

a. Lower reproductive tract

A reproductive system disease is any disease that impairs the ability to reproduce. Such diseases may arise from genetic or congenital abnormalities, from functional problems, (such as impotence or infertility), or reproductive tract infections, (such as sexually transmitted diseases) or FGM. Problems with the lower reproductive tract in women may be located in the vagina, cervix and vulva.

The vagina, or birth canal, is a tube about 10-15 cm long with smooth muscle walls and a lining of pink tissue called a scale layer. Normally the vagina walls lie opposite each other and they have ability to stretch to accommodate the descent and exit of the baby during child birth. The healthy vagina has a colony of symbiotic micro-organisms that protect the host from disease-causing microbes; anything that upsets this balance is likely to cause ill health.

The acidity of a healthy vagina of a woman of child-bearing age (pH of around 4.5) prevents the growth of infection, and secretions in the vagina help establish an environment that checks the growth of the micro-organisms there and keeps them in balance. FGM can disrupt this system leading to some of the micro-organisms multiplying quickly and leading to an infection, which requires medical attention and treatment (Kliegman, 2011).

b. Infections and anatomical damage from FGM

Studies of systematic comparisons of circumcised and uncircumcised women indicate that circumcised women are at higher risk of anaemia and some infections. For example, in

Gambia, a study that attained laboratory confirmation of infections (Morison et al., 2001) reported that non-specific vaginitis and herpes virus (HSV2) were more frequent among circumcised women, but syphilis was less common and there were no significant differences in the incidences of candida, chlamydia, and trichomoniasis.

Controlled studies in Tanzania (Klouman et al., 2005) showed no difference in pelvic inflammatory disease (PID), candida, chlamydia, trichomoniasis or human immunodeficiency virus (HIV) but found a higher frequency of non-specific vaginitis that was not statistically significant. In Nigeria, a study based on women's reports, hence using less precise categories of complications (Okonofua et al., 2002), found that abdominal pain, discharge and genital ulcers were more frequent among circumcised women. Only one controlled study considered urinary symptoms (Morison et al., 2001), and it found no significant difference in urinary incontinence. With regard to gynaecological effects, controlled studies indicate increased risks of reporting abdominal pain, discharge and ulcers among circumcised women in Nigeria (Okonofua et al., 2002), and general gynaecological problems in Mali and Burkina Faso (Jones et al., 1999), but lower risks of prolapse in Gambia (Morison et al., 2001).

c. The mechanism by which FGM causes adverse obstetric outcomes

There is evidence that FGM is associated with increased rates of genital and urinary tract infection that might have repercussions for obstetric outcomes (Jones et al., 1999; De Silva, 1989; Morison et al., 2001). Extensions of the length of the second stage of labour are unable to be measured reliably, because good obstetric practice discourages frequent vaginal examinations. Furthermore, the increased risk of caesarean section in women with FGM type II or type III could theoretically lead to an underestimation of the effect on the length of the second stage of labour in women with these types of FGM. Scar tissue from FGM is less

elastic than the perineum and causes problems during the third stage of labour. The direct effects on the perineum might underlie the findings of an increased risk of perineal injury, postpartum haemorrhage, and the need for resuscitation of the infant after birth among women with FGM.

d. Urine retention and FGM during labour

Four early studies pointed out the problems of FGM and urinary retention during labour. Shandall (1967) described five cases out of 1245 Sudanese obstetric cases seen over a five-year period, where urethral catheterisation was difficult due to the presence of FGM type III. In all five cases, de-infibulation was required so that a urinary catheter could be inserted.

Modawi (1974) reported, in what seems to be a personal observation in a case series in Sudan that the retention of urine in labour is common and insertion of a catheter is difficult. It is unclear whether this statement refers to FGM type III alone or FGM Types I, II or III, which are all mentioned in the study.

Baker et al., (1993) in the USA outline one case in which catheterisation during labour was difficult in a Somali woman with FGM type III. McCaffrey et al. (1995) described a case of a Somali woman with FGM type III giving birth for the first time in the UK. Her FGM resulted in a vaginal entrance so small that it would barely admit one finger. She had to be de-infibulated to enable the insertion of a urethral catheter, prior to an emergency caesarean section to enable the child to be born.

In each of these four studies, urine retention in labour appears to be a problem mainly among women with FGM type III and Modawi's (1974) report on seven cases in relation to Somali or Sudanese women implies many more women may be affected by this problem.

e. Foetal distress and FGM during labour

Shandall (1967) in a cross sectional study in the Sudan describes two cases; in one case, the baby's distress necessitated an instrumental delivery and, in the other case, both mother and baby were in difficulty which necessitated a caesarean section. No definition of new-born baby distress was given in this study and the type of FGM was not stated.

Berardi et al. (1985) undertook a large comprehensive case control study among French speaking African women in France with FGM type II. The authors reported no significant difference between the rate of new-born baby distress in a hospital setting between babies of mothers with FGM type II and those of mothers without FGM. There were two out of 71 cases of measurable new-born baby distress in the FGM group (2.8%) and 18 out of 781 cases of foetal distress in the non-FGM group (2.3%). Chi square analysis showed no significant difference between the two groups in terms of foetal distress.

De Silva (1989), however, shows that FGM of all types has a significant effect on neonatal condition. In a cross-sectional study 2157 Sudanese women 167 mothers with FGM, (20 type I, 76 type II and 71 type III) were compared with 1990 non-FGM mothers (De Silva, 1989). There was a significantly higher rate of foetal distress among the babies for FGM mothers compared to non-FGM mothers as demonstrated by lower Apgar scores for the babies of FGM mothers at five minutes. Nine of the 167 (5%) neonates of mothers with FGM had Apgar scores of less than five at five minutes compared with 48 of the 1990 (2%) neonates from the non-FGM group. This is significant at $p < 0.05$ (using Student's *t*-test). For the measurement of Apgar scores the groups of neonates were not subdivided according to whether their mothers were FGM type I, II or III, which would have provided further useful information.

2.3.3 Upper reproductive tract

a. General

Other reproductive organs such as the uterus, fallopian tubes and ovaries are not directly affected by FGM, but the consequences of FGM may affect a woman's upper tract reproductive organs through infection. Some of the most serious consequences occur when an outside organism or infections of the lower genital tract e.g., the cervix or vagina, reach the upper genital tract (the uterus, fallopian tubes, ovaries and surrounding structures). Infections may become generalised and life-threatening. The resulting tissue damage and scarring may cause infertility, chronic pelvic pain and increase the risk of ectopic pregnancy. One early study estimated that 20%-25% of cases of sterility in northern Sudan can be linked to infibulations (Mustafa and Erwa, 1972). The uterus, cervix, and related structures share the same visceral nerve supply as the lower ileum, sigmoid colon, and rectum. Because of this shared pathway, distinguishing between pain of gynaecological and gastrointestinal origin is often difficult.

Both the uterus and pelvic floor structures are important to the health of the upper reproductive tract. The uterus is a hollow, pear-shaped organ, located in a woman's lower abdomen, between the bladder and the rectum and it is the organ of pregnancy. Implantation of a fertilized egg normally takes place 6-12 days after ovulation once sperm from the male move through the fallopian tube to unite with the egg. The pelvic floor is responsible for active and passive support of the bladder, vagina, and anus-rectum. Damage to these structures may result in loss of support and loss of the normal function of the urethra, bladder, and/or rectum. Over time, this damage can result in isolated or combined pelvic organ prolapse, including the vagina, the uterus and accompanying urinary incontinence, and/or anal incontinence (Llewellyn-Jones et al., 1999).

b. Pelvic Inflammatory Disease (PID)

Pelvic inflammatory disease is an infection that can affect a female's reproductive organs. As it progresses it leads to scar formation with adhesions to adjacent tissues and organs and this, in turn, leads to further infections. Infection spreads upward from the cervix to the uterus, fallopian tubes, ovaries, and adjacent structures and appears as cervicitis (inflammation of the cervix); salpingitis (inflammation of the fallopian tubes); endometritis (inflammation present in the lining tissues of the uterus); and peritonitis (inflammation of the peritoneum, the membrane that lines the abdominal cavity and covers most of the abdominal organs).

All these situations might be seen as specific diseases; but many investigators group them together as variations of PID, especially if they are caused by chlamydia, trichomoniasis or *Neisseria gonorrhoea*.

The rate of PID in infibulated women is three times that in women with clitoridectomy only, and the rate of PID in women who have undergone clitoridectomy is often higher than that in women without FGM (Shandall, 1967). The possible causes for these rates are infection at the time of the FGM procedure, interference in the drainage of urine and vaginal secretions, and postpartum wound infection. PID is not only painful but can also lead to infertility because of scarring of the fallopian tubes. The contribution of infibulations to the high levels of infertility in Africa is contested, but some studies have claimed a high contribution (Mustafa, 1996).

Even though the PID infection itself may be treated effectively with antibiotics this is often a complex process so prevention and early diagnosis are important. Strong evidence suggests that neither the site nor the route of antibiotic administration affects the short or long term major outcome of women with mild or moderate disease. Data on women with severe disease was inadequate to influence the results of the study (Walker and Weisenfeld, 2007).

Infertility can be an important consequence of FGM in young girls (Almroth, 2005b). Traditionally plastic surgery was the core approach to correct tubal blocks or adhesion formation; however, successful recovery is limited. Recently in vitro fertilisation has proven to have a better outcome for those wishing to become pregnant (Andreoli et al., 2010).

c. Ectopic pregnancy and complications

Ectopic pregnancy usually occurs in the uterine fallopian tube when the passage of the fertilised ovum through the uterine tube is impaired. The cause may be decreased motility of the uterine tube or abnormal anatomy, including scarring from PID, previous uterine tube surgery, and previous ectopic pregnancy. Other causes included repeated elective abortions, pelvic tumours and developmental abnormality (Llewellyn-Jones et al., 1999).

Treatment of ectopic pregnancy is an obstetric emergency and requires surgical intervention. Therefore, early prevention suggests that high risk groups, such as African women with FGM, need to consult their doctor to ensure early diagnosis and appropriate treatment (Andreoli et al., 2010).

2.3.4 Normal labour

Normal labour is defined as uterine contractions that result in progressive dilation and the shortening or thinning of cervix as it prepares for childbirth. The fibres of the upper uterine segment have powerful forces that facilitate contraction, relaxation and retraction during labour. The progress of retractions is gradual, slowly rising in frequency, extent and power. Eventually, they take place at a frequency of around one every three minutes, lasting for one to two minutes with one to two minutes active relaxation between them until the cervix is fully dilated. The mucus glands of the cervix secrete mucus that makes the cervix become soft and thinner. The elastic sides of the vaginal channel from the cervix to the vulva work to deliver the infant from the uterus to its independent life outside the body of the mother. The

natural labour mechanism has powerful forces enabling it to expel the baby, the associated placenta and membrane through the maternal passages. Finally, the corrective pressure relationships between the baby's head and the lower uterine segments are vital to this mechanism labour (Beazley and Kurjak, 1972).

a. The impact of FGM on the natural labour mechanism

FGM results in a direct mechanical obstacle to natural labour that may be severe and directly responsible for both maternal and infant deaths. FGM type III creates a mechanical obstacle caused by the creation of a much smaller than normal opening through which the baby has to pass. If this is not opened up surgically (de-infibulation) the exit of the baby's head may be obstructed. Strong contractions will lead to a perineal tear that may extend to the anal sphincter or rectum. If contractions are weak and delivery of the head is delayed, the baby may die. The wall between the vagina and bladder can break, which creates a hole between the bladder and the vagina causing a distressing condition of urinary incontinence that often results in women being ostracised by their communities (Egwuatu and Agugua, 1981).

A circumcised mother is unlikely to deliver without assistance because of the high risk of severe perineal lacerations, bladder-vaginal fistulae, excessive bleeding and infections. An episiotomy sufficient to divide the circumcision scar is necessary in all patients, and sometimes antenatal surgery is required (Egwuatu and Agugua, 1981).

b. Prolonged labour and/or obstruction in women with FGM

Prolonged labour and/or obstruction in women with FGM appears to be one of the most frequent obstetric outcomes of FGM. De Silva's 1989 case control study of Sudanese women in Saudi Arabia provides substantive evidence for FGM causing a prolonged second stage of labour. This showed that for 167 Sudanese women with FGM (compared to a control group of 1990 women without FGM) the duration of the second stage of labour was prolonged both

for those at first delivery (more than 90 minutes), and for those giving birth for a second or later delivery (more than 60 minutes), with statistical significance at $p < 0.001$. Twenty-three of the 167 women with FGM (14%) had prolonged second stage of labour compared to 86 of the 1990 women without FGM (4%). There was no difference found in the duration of the first stage of labour for the women with or without FGM. Types I, II and III were represented in the FGM group in this study. Other studies (Harris and Angawa, 1951; Lister, 1960) have reported similar findings, recognising that the degree of severity of FGM and parity will influence obstetric outcome.

Harris and Angawa (1951) reported on a case series in Kenya among Kikuyu women with a ruptured uterus. The women were seen over a period of three years in Kiambu where FGM type II is practised. The study showed that the use of an episiotomy can generally overcome delay or obstruction. In Nigeria, Lister (1960) reported on a case series of 320 women with obstructed labour, and argued that the scarring from FGM seen in the region (probably FGM type I/II as practised among the Yoruba and Ibo) was never severe enough to cause obstruction and its sequelae. However, the article also describes three cases of vaginal stenosis (blockage) two of which were caused by insertion of native herbal pessaries. This is an example of FGM type IV, with pessaries used as a treatment for sterility, threatened abortion, or to restore menstrual function. Vaginal stenosis is stated to be a cause of obstructed labour and its consequences.

c. Vaginal blockages as a cause of obstructed labour in women with FGM

Pritchard (1969) describes prolonged second stage of labour due to vulval scarring in three Sudanese women in the UK with FGM type III. Daw (1970), reporting on three cases of Sudanese women with FGM type III (delivering in Sheffield), found that the length of the

second stage of labour was prolonged in two cases, one was a first delivery and the other was a second or later delivery, but both women required forceps delivery.

Brown and Rae, (1989) in a postal survey of English-speaking Somali women in Canada found that only six of 105 respondents had given birth. Of these six, five women reported the length of labour to be 24-73 hours; neither FGM type nor number of births was stated.

Arbesman et al. (1993) in a series of personal interviews with 10 Somali women in the USA found that labour lasted up to two days. There is no mention of either the type of FGM nor the numbers of births, although FGM Types I and III were represented in the sample.

Overall, the obstruction described by the above studies relates to soft tissue scarring in the vulva. Many cases of such obstruction are described as being easily overcome by episiotomies prior to delivery. The delayed labour relates to the second stage in all but one of the studies. Only one study reported on the effects of FGM on delay in the first stage of labour.

2.3.5 Risks of excessive bleeding (haemorrhage)

A number of papers have reported on the risks of excessive bleeding associated with FGM. This may occur in late pregnancy, during childbirth or postpartum.

Rwiza et al. (1980) described a case of a woman from the Pare tribe (Tanzania) with FGM, type not stated, but probably type II, who had severe postpartum haemorrhage from vulval tears.

McSwiney and Saunders (1992) depict a Somali woman's first pregnancy in Bristol in the United Kingdom (UK) where she suffered an estimated six litre blood loss from vaginal and perineal tears sustained following delivery in the presence of FGM type III. The woman also required a period of intensive care for 24 hours and blood transfusions.

Odoi et al. (1997) reported 20 out of 76 first pregnancies in Ghanaian women with FGM type I or type II as having obstetric complications in terms of lacerations or haemorrhage.

Adetoro et al. (1986) described a case of a Nigerian woman who required a blood transfusion of two units of blood on admission to hospital because of bleeding at the time of FGM type II (performed in the third trimester of pregnancy before the start of labour).

2.4 Psychological impacts of FGM

2.4.1 Mental health impacts

“I was eight when it happened. I still feel hurt and aggrieved about it like there is something missing and I am not a real girl ... My aunt, her sister, my mother and some neighbours held me down... and they didn't give me any anaesthetic” (Dorkenoo, 1994)

The psychological complications of FGM may be buried in the child's subconscious. This may trigger behavioural disturbances. In the longer term, women may suffer feelings of incompleteness, anxiety, depression, loss of trust, chronic irritability and frigidity. Many women and girls, traumatised by their experience but with no acceptable means of expressing their fears, suffer in silence. On the other hand, immigrant females in cultures with different or "more liberal" attitudes towards sexuality may face challenges or distorted expectations from the new sexual culture, media or new peers. The circumcised female, aware of differences in the appearance of her genitalia, may feel deeply embarrassed during clinical examinations.

In contrast to the numerous studies and case reports on the physical effects of FGM, little scientific research is available on the sexual and psychological effects of FGM. It is evident that severe pain can result in deep psychological wounds, leaving painful memories and

emotional scars. Toubia (1995) maintains that during her clinical experience in Sudan many infibulated women had a syndrome of chronic anxiety and depression, arising from worry over the state of their genitals, intractable dysmenorrhea, and the fear of infertility. Her observations also confirm that many women feel a sense of a loss of trust and confidence in those that are caregivers, especially their mothers.

Girls and women, who have undergone FGM, have adverse effects on their mental health. For instance, some researchers assert that FGM represents a violation of women's physical intactness and can be classified as a "psychological trauma and a potential cause of post-traumatic stress disorder" (Behrendt and Moritz, 2005). Toubia (1994) found that many infibulated women in Sudan undergo chronic anxiety and depression as a result worry over their FGM status. A qualitative study of the psychosocial impact of FGM among Bedouin Arabs in Israel revealed that women with FGM had various emotional struggles and psychosocial problems, such as a loss of trust in the mother-daughter relationships. Women reported feelings of fear, helplessness, and anger related to FGM. One said, "I perceive it as abuse" (Al-Krenawi et al.). Recently, Vloeberghs and colleagues (2010) interviewed 66 women with various types of FGM. Most of the women, who lived in the Netherlands, reported a number of psychological consequences from FGM, as well as anxiety, bad memories and stress. Conversely, many women with FGM, while they were in their home countries reported feeling proud (Chalmers and Hashi; 2000) and some argued that having FGM was very positive for them: "I was very happy to go through it since I had been looking forward to it" (Mwangi-Powell, 1999).

Psychosocial and sexual problems are identified by interviewing clients using interpersonal communication, observation and listening skills. Because of the sensitivity of the subject, a woman will rarely speak directly about a psychosocial problem, but will tend to present with some physical complaint. It is essential for the doctors, nurses, midwives and counsellors to

pick up non-verbal signs of psychosocial problems, by observing body language and listening carefully to the tone of voice, which may give more meaning to what the client is saying by revealing their underlying feelings. Toubia (1998) highlights the need for this in his article for WHO:

“Thousands of women present themselves with vague complaints all metaphorically linked to their pelvis, which really means genitals since they are socially too shy to speak of their genitals. They complain of symptoms of anxiety and depression, loss of sleep, backache and many other complaints uttered in sad monotonous voices. When I probe them a little, the flood of their pain and anxiety over their genitals, their sexual lives, their fertility and all the other physical and psychological complications of their circumcision is unbearable. These women are holding back a silent scream so strong, if uttered it would shake the earth....” (WHO, September 29, 1998. Article, p.715)

2.4.2 Fear of medical interventions

Fear of medical investigations, labour and delivery, due to the small size of the vaginal opening, and a need for appropriate obstetric care is widely acknowledged among women who have experienced FGM, and is demonstrated by the studies discussed below.

Modawi (1974) in a case series of 3000 women in Sudan concluded that women with FGM approach labour in “a state of fear”, but no statistics are given. FGM Types I, II and III were represented in the series.

Shaw (1985) conducted a series of interviews with 12 women with FGM (type not stated, probably III) from Sudan, Egypt and Somalia, who had received medical, mainly obstetric, care in the USA and found that 100% (12) were worried about painful pelvic examinations and 90% (11) were worried about tearing of infibulation scars during delivery and incorrect suturing after delivery.

Brown and Rae (1989) identified six English-speaking Somali women in the towns of Mogadishu, Hargeysa and Lefoole with FGM type III who had already given birth. The women all recalled concern regarding about the size of their vaginal openings for childbirth and some had tried to limit foetal growth to ease childbirth.

2.4.3 Psychosomatic problems

Girls and women who have undergone FGM might attend a health service complaining of a broad variety of physical problems that are not described in medical literature. Such symptoms are psychosomatic i.e., psychological problems that the client experiences as physical discomfort. Worry about genitals or about sexual associations may evidence itself in psychosomatic symptoms. Often the girl or woman is unaware that her symptoms are based on psychological anxieties. In some cases, she may be conscious that the symptoms she is presenting are not the real cause of her problems, but she is too shy to talk about them directly and attends the clinic hoping that the health care provider will be competent to support her. Black and DeBelle (1995) suggest that this is less likely to be a problem among those living in societies where FGM is routine, as the woman's experiences are seen as normal.

2.4.4 FGM and sexuality

It is difficult to assess the impact of FGM on women's sexual fulfilment as each individual woman with FGM will be affected differently. Factors like the type of FGM, the amount of tissue removed, the degree of scarring, the experience of the initial procedure, cultural and social expectations, and affection and bonding in sexual relationships will all directly affect sexuality and sexual functioning. Painful intercourse (dyspareunia), orgasmic delay and anorgasmia are common (Brighouse, 1992). Many women who have undergone FGM experience various forms and degrees of sexual aberration, report altered mental states or

emotions. These may include fear associated with initial sexual intercourse; pain associated with sexual intercourse; difficulty with, or an inability to have, sexual intercourse; and decreased sexual pleasure and fulfilment. Emotional or physical pain during intercourse diminishes the enjoyment of both the woman and her partner (Longmans et al., 1999), which might have implications for intimacy in the relationship.

FGM potentially causes a host of sexual problems. Dyspareunia, orgasmic delay and absence of orgasms or complications from genital surgery are common (Brighouse, 1992). However, these may not be perceived as a problem if the girl underwent the procedure before becoming sexually active. Orgasmic difficulties are more likely to be reported in groups that undergo the procedure after period of adolescent sexual activity or just prior to childbirth. El-Defrawi et al. (2001) observed significant rates of sexual difficulties in 80% of a female circumcised population, namely, lack of desire (45%), reduced pleasure (49%) and orgasmic failure (60.5%).

The effect of FGM on a woman's sexual experience varies depending on many factors. FGM does not eliminate all sexual pleasure for all women who undergo the procedure, but it does reduce the likelihood of orgasm. Stimulation of the clitoris is not solely responsible for the sexual excitement and arousal of a woman during intercourse; this involves a complex series of nerve endings being activated and stimulated in and around her vagina, vulva (labia minor and major), cervix, uterus and clitoris, with psychological response and mind-set also playing a role (Komisaruk et al., 2008).

Lightfoot-Klein (1989b) studied circumcised and infibulated females in Sudan, stating "Contrary to expectations, nearly 90% of all women interviewed said that they experienced orgasm (climax) or had at various periods of their marriage experienced it. Frequency ranged

from always to rarely." (Lightfoot-Klein, 1989b, p. 375-392) The quality of orgasm was reported as varying from intense and prolonged, to weak or difficult to achieve.

A study in 2006 found that in some infibulated women, some erectile tissue fundamental to producing pleasure had not been completely excised (Catania et al., 2007). De-infibulation of subjects revealed that either a part or the whole of the clitoris was underneath the scar of infibulation. The study found that sexual pleasure and orgasm are still possible after infibulation, and that they rely heavily on cultural influences — when mutilation is lived as a positive experience, orgasm is more likely. When FGM is experienced as traumatic, the frequency of sexual pleasure and orgasm drops. The study suggested that FGM women who did not suffer from long-term health consequences of FGM and who were in a good and fulfilling relationship may enjoy sex.

FGM has been associated with infertility in some cases (Eke and Nkanginieme, 1999). This can be attributed to complications arising from the introduction of infection such as PID, the formation of scars, or even from inadequate penetration during sexual intercourse. Emotional or physical pain during intercourse diminishes the enjoyment of both the woman and her partner with the woman being reduced to a masturbatory object during sex (Longmans et al., 1999). This certainly has implications for intimacy in the relationship.

2.4.5 Cultural stigma

Cultural stigma can occur for both those who are circumcised and those who are not. The contribution of infibulation to the high levels of infertility in Africa is contested, although one study claims a high contribution (Mustafa, 1966). In addition, infertility in communities where childbirth and child rearing play a major role for women should not be underestimated. In some societies the failure to produce children is blamed on women, and may even be attributed to a curse. This can result women being rejected by their husbands and even by

their extended families, resulting in further social isolation. On the other hand, girls who are not infibulated might experience harassment and teasing and might encounter difficulties in getting married.

2.5 De-infibulation

According to researchers and observers, marriage and sexuality are key reasons for the practice of genital mutilation:

“Marriage, or future marriage, and sexuality are central in the context of FGM, and the practice is often seen as a symbol of decency, dignity and fertility.” (Almroth, 2005)

De-infibulation is a surgical technique to reverse the closure of the vaginal opening after a type III infibulation, and consists of a vertical cut opening up normal access to the vagina (Nour et al.; 2006). A tightly infibulated young woman needs de-infibulation. This may be requested prior to marriage to permit penile access. A virgin woman has to undergo gradual dilation of the vaginal opening, in order to enable the husband to be intimate with her. This process facilitates intercourse and may relieve dyspareunia. Otherwise, excessive penile force during the first intercourse can cause severe bleeding, shock, infection and anxiety. In Australia, de-infibulation is considered a form of corrective surgery performed by a gynaecologist. De-infibulation can alleviate some of the common complications listed above.

The health benefits of de-infibulation include improved menstruation, improved urination, improved sexual intercourse and childbirth. In some communities, it is customary for infibulations to be reversed just before marriage, or immediately after marriage, to facilitate consummation and subsequent childbirth (McCaffrey et al.; 1995). This reversal is often carried out by a birth attendant or a midwife.

Some women request that only a very small vulva opening is made during surgery. This is an important chance to discuss and dispel the myths surrounding the need for a "tight opening"

and explain the importance of a wide vulval opening so that there is enough space for vaginal examination to monitor progress of the baby's head during labour. In some western countries or even parts of Africa, however, many women find it difficult to obtain this service, as they either do not know that such services exist or do not know how to access them. In addition, they may feel that it is culturally inappropriate to ask for help. As a result, consummation may be achieved solely by penile penetration, but the vaginal opening remains too small for natural vaginal delivery of a child (McCaffrey et al.; 1995).

2.5.1 Physiological changes post De-infibulation

Women need a clear explanation regarding the changes associated with urination, menstruation and sexual intercourse following de-infibulation. Passing urine will be quicker, menstruation might become heavier and sexual intercourse through a wider vaginal opening could provide new sensations for both partners (Momoh, 2003).

Infibulated Sudanese women normally undergo re-infibulation after giving birth (the Sudanese-Arabic term is "adal" or "al-adil", which in this context means to rectify and improve) through re-stitching the vagina, and tightening the vaginal orifice (Almroth 2005). Studies from the early 1980s showed that 50%-80% of the female respondents had been re-infibulated. The tightening of the vaginal orifice after giving birth and the belief in the "purity" of a tight vaginal opening were important factors for the female respondents. Some of the women also referred to enhanced aesthetics of the sexual organs as an argument for re-infibulation (Berggren et al., 2007).

There is very little information available on how widespread re-infibulation is among Somali women in Somalia and elsewhere. Some sources claim that in general, women are re-infibulated after giving birth. Yet a study conducted among Somali women in Norway

(Johansen, 2002) showed that there was in fact no such firm basis to support the assumption that re-infibulation is common after giving birth.

2.6 Implications for healthcare professionals

2.6.1 Introduction

Women with FGM are migrating to western countries where few health providers have seen or know the consequences of FGM. Most health care providers in western countries have not had experience in assisting women with FGM during pregnancy, childbirth or after childbirth. That could put pressure on health care services where the professionals may lack necessary knowledge and skills to enable them to care for these circumcised women.

Existing literature published on the subject of FGM, its medical consequences and complications (De Silva, 1989; Toubia, 1994; McCaffrey, 1995) showed that circumcised women may go through pregnancy without a midwife or doctor acknowledging, examining and/or documenting the circumcision.

Before ultrasound became common, an obstetrician would normally examine the women vaginally around the 12th week of pregnancy, primarily to confirm and date the pregnancy and to exclude other problems.

A circumcision identified during pregnancy could adversely influence the birth experience and possibly the outcomes. It has been suggested that there may be a higher incidence of emergency caesarean sections among circumcised women than among non-circumcised women (Toubia, 1994). This could well be because the staff, who are attending the circumcised woman, are not well prepared to deal with the consequences of the changed anatomy and might have difficulties in assessing the progress of labour and the well-being of both the baby and the mother.

FGM presents dilemmas for both midwives and women with each of them reacting from their own context of traditions and culture, gender and lay or professional perspectives. Infibulation is a practice with far reaching consequences for the health of women. Perhaps a better understanding of and sensitivity to the social and cultural meanings of female circumcision by health professionals, coupled with medical knowledge and skills, would help ensure appropriate health care provision.

2.6.2 The "unspoken problem" for women with FGM and health professionals

In some countries women with FGM go through their antenatal care with little or no attention paid to their FGM. It is an issue that is not spoken about. The women with FGM do not speak about it because of embarrassment or they do not know what to say, and the health professionals do not always address the issue either because they do not know how to respond culturally or as health professionals or through lack of processes.

The care of infibulated women during pregnancy and childbirth seems to be a marginalised issue in some western countries. Early acknowledgement of FGM during pregnancy as well as improved communication between health care units may help professionals to offer culturally sensitive professional care to the women and their families (Widmark et al., 1998). Widmark and Ahlberg. (2002) provide an example of issues in the care of FGM women in Sweden. The data in this study highlighted communication problems at different levels between midwives and the women and their families. There appeared to be no Swedish guidelines in the units on how to provide good care for infibulated women and little or no co-ordination between antenatal and childbirth care (Widmark et al., 2002).

Garvey-Graham (2008) reported on the experience of midwives caring for women with FGM in Wellington, New Zealand. This was a qualitative study of four independent midwives, with experience ranging from ten years to over twenty years. Three participants had completed

their midwifery training abroad, after working as registered nurses. The participants had worked in a variety of practice settings over the years and by sharing their experience, they were aware that they could contribute to expanding midwifery knowledge concerning FGM.

Four themes emerged:

- feeling unprepared
- negotiating the cultural gap
- finding the reality of de-infibulation traumatic
- dealing with tensions and paradoxes

a. Theme one: Feeling unprepared

The first of these themes, feeling unprepared, reflects the scarcity of relevant information and education available to the midwives in their first experience in caring for women who had FGM type III. All of the midwives who participated reported their inadequate knowledge of FGM type III.

One midwife reported that the entire learning experience provided by her midwifery training was not adequate for caring for circumcised woman in maternity care. As a young midwife, when she first encountered FGM, her first feeling was of terror – because she had no cultural comprehension of FGM and was unable to recognise it anatomically or physically. She started thinking, how did this woman conceive? Was the woman more likely to have recurrent urinary tract infections? How was she going to take care of the woman during childbirth? This lack of knowledge made it difficult for the midwife to care appropriately for the woman.

b. Theme two: Negotiating the cultural gap

It is significant that there was an apparent absence of formal midwife education regarding the care and management of women who have FGM type III. Not only was there no information on this topic in the midwifery curriculum of the time, but there were insufficient educational opportunities relating to it in on-going professional development. These deficiencies will inhibit midwife professional growth if left unaddressed.

One midwife reported seeing a woman with FGM type III late in the second stage of childbirth pushing the baby's head into a small vaginal opening. The midwife found herself wrapped in her thoughts, worrying about how to deal with the situation. Then she gathered herself together and responded to the woman and her husband, who pointed where to cut. The midwife followed her instinct and felt the best way to take care of the situation was to cut where he was pointing. This created an opening of sufficient size to enable a safe delivery and prevent tearing of the vagina or perineum.

c. Theme three: Finding the reality of de-infibulation traumatic

Midwives reported that both the health provider and women in labour are confused by the situation and high levels of stress are the outcome. Both women and midwives may have a history of prior events, with these memories creating more stress and trauma. FGM is a sensitive and complex matter, and talking about it can make health professionals feel uncomfortable. Their reluctance to engage with women about FGM may relate to embarrassment, uncertainty about how to frame the questions on the subject and/or anxiety about being culturally insensitive.

d. Theme four: Dealing with tensions and paradoxes

Midwives were aware that re-suturing to recreate a smaller opening (re-infibulation) is undesirable from a health perspective and also illegal in New Zealand, despite wishes

expressed by women who wanted to return to the vaginal tightness of their pre-childbirth state. The 1996 amendment to NZ Crimes Act 1961 identifies that "any act involving female genital mutilation" is illegal (Section 204A, points 2 and 6 respectively). The potential future health problems from re-suturing need explaining. In areas where FGM type III is virtually universal, should re-suturing be refused after delivery, it is likely that the woman will find someone willing to do the re-suturing later, often because of direct or indirect pressure from her husband or friends or family (Berggren et al., 2007). However, this is not known to be the case in New Zealand.

2.6.3 Guidance for health professionals

a. Management of FGM type II or III women during antenatal care

Where the vaginal opening is very small, there is insufficient space to assess the degree of cervical opening during labour. If there is a problem of assessment, the scar can be opened with appropriate anaesthesia (using either a cream or a local anaesthetic). Although this is often done during the second stage of labour, it is recommended that it be done during antenatal care after the 28th week of pregnancy and before labour. This avoids health professionals, who may be unfamiliar with the procedure, being confronted with the need to do it during labour (McCaffrey et al., 1995). The success of de-infibulation for the restoration of women's anatomy is in some cases as high as 60% with all functions being restored (Jones et al., 1999).

b. Management of women with FGM types II or III during childbirth

De-infibulation can be done at the height of a contraction with an effective anaesthetic cream or a local anaesthetic. More often than not there is little bleeding from the scar tissue as there are few blood vessels in this tissue. The incision should not be extended beyond the urethra –

doing so creates no extra space. On average, this will leave 4-5 cm of the old scar unopened as the mutilation always extends to the clitoral area (Jones et al., 1999).

Suturing the cut should be postponed until after delivery. With a wider opening, normal assessment is possible, and a decision about a mid-line cut can be delayed until the second stage of labour. If no incision is made during the second stage of labour it might lead to more difficulties with the baby's head being delayed by the scar tissue. This is unsafe for both the mother and baby as unrestrained tears can take place and the new born baby can become severely oxygen deficient leading to potential brain damage. Performing a mid-line cut during antenatal care or during the second stage of labour minimises trauma to both mother and child (McCaffrey et al., 1995). Many pregnant women prefer that de-infibulation be performed during delivery, just as an episiotomy is, instead of having to undergo what they perceive as a stressful event during their pregnancy (Thierfelder et al., 2005).

c. Postpartum care of women with FGM for inexperienced midwives

Major complications could occur immediately following delivery with extensive lacerations and haemorrhage from tears in addition to the usual puerperal difficulties. Extensive uncontrolled lacerations result if the woman has delivered through an intact scar, or if an incision has been incorrectly performed. Extensive tears may involve the urethra, bladder and the rectum. The dangers of delivery for women with FGM are lessened if they deliver in a hospital setting with experienced skilled attendants such as a midwife or obstetrician practising safe techniques for the incision of vulval scars.

2.7 Conclusion

FGM persists, with approximately 80–115 million women subjected to FGM globally, and two million girls at risk annually (Dorkenoo, 1994; WHO, 1996). This is despite efforts to eradicate the tradition and an increased awareness of the detrimental medical and

psychological consequences of FGM. This literature review has considered the way in which FGM affects the health and well-being of women throughout their lives in terms of their physical, psychological and mental health. There is particular concern for women as they undergo pregnancy and childbirth. In New Zealand at least, health providers attending circumcised women are not well prepared to deal with the consequences of the changed anatomy and might have difficulty both assessing the progress of labour and also applying modern technology to evaluate the baby's and mother's wellbeing.

FGM has no known health benefits; indeed, there is widespread recognition that it has many unwanted consequences. Strong evidence to support this is limited because research into FGM is complicated by difficulty in defining variable surgical procedures and the problems of conducting research in resource poor environments (Mahklouf-Obermeyer, 2005).

Healthcare professionals are involved in counselling and educating women during antenatal care about de-infibulation; but despite this many pregnant woman continue to reject de-infibulation throughout pregnancy. De-infibulation then becomes necessary during the second stage of labour.

From this review, it is clear that there are unmet needs among women with FGM in western countries, and the remainder of this thesis examines how East African women living in Christchurch and their health providers view their situation and how the needs of the women can best be met.

Chapter 3: Research Methods

3 Overall approach

This section presents the principles and concepts underpinning the research process. Because the overall purpose of this research is to understand the situation of both Christchurch women with FGM and their health providers, in order to increase knowledge of FGM and ensure improved health services for women with this condition, it was decided that qualitative descriptive research methods would be most appropriate.

Qualitative research is a form of social investigation that focuses on the way people interpret and make sense of their experiences and the environment in which they live (Holloway and Wheeler, 2002). It will allow a detailed exploration of women's perspectives of FGM. The complex nature of the impact of FGM on the health of this community can be better assessed using this approach through hearing the stories of their experiences during antenatal care, childbirth, postpartum care and other contacts with health providers. The views of health providers provide an important perspective too. This methodology is especially suited for working with marginalized populations such as refugees and migrants, particularly because of the ethical issues involved for obtaining informed consent, and a consideration of the risks and benefits for the community (Ellis et al., 2007).

Qualitative descriptive studies offer a "comprehensive summary of an event" (Sandelowski, 2000, p. 336) and so this method has been chosen to develop an understanding of how FGM affects the health of female East African migrants and refugees living in Christchurch, and how their health providers care for them. The literature review in Chapter Two revealed that the care of infibulated women during pregnancy and childbirth can be difficult. Although this matter is now addressed in many western countries such as Sweden and the UK, many

medical professionals in New Zealand and other western societies lack knowledge of this matter due to insufficient training and understanding of the issue. They therefore cannot adequately meet the needs of these women and provide proper health care for them.

The research for this thesis made use of the focus group method to seek data from women in Christchurch who had experienced FGM but individual semi-structured interviews were used with service providers.

3.1 Focus group method

Powell et al. (1996) define a focus group as a set of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research.

In the context of healthcare and medical research, the use of focus groups is particularly apt as most health-related conditions are created by social environments and are thus derived from social contexts (Carter and Henderson, 2005). Focus group discussions are frequently used to obtain knowledge, perspectives and attitudes of people about issues. They are also useful for seeking explanations for behaviours in a way that is more acceptable than one-to-one interviews (Kreuger, 1988; Kitzinger, 1995). Focus groups can also be used to gain insights into people's experiences of ill-health and health services (Naish et al., 1994; Murray et al., 1994) and discover the attitudes and needs of healthcare providers (Denning and Verschelden, 1993).

Thus, focus groups are useful for assessing personal experiences and understanding of health and illness (Kitzinger, 1993) by identifying ideas concerning health-risk behaviours and danger (Ritchie et al., 1994). Trilling (1999) adds that they are also useful for discovering the public's perception of the causes of diseases. Focus groups are also effective for the study of

sensitive issues that are too difficult to access by other means, issues such as sexual health matters and FGM. For example, Naish et al. (1994) and Murray et al. (1994) note that they can also be used to gain insights into people's experiences of illnesses, such as recurrent urinary infection, or health and health services. Denning and Verschleden (1993) value focus groups as a vehicle to explore the attitudes and needs of healthcare providers, for example, examining communications between consumers and health providers that are appropriate to their culture and language within a supportive environment.

Focus groups are a form of group interview that capitalize on communication between research participants in order to generate data. Although group interviews are often used simply as a quick and convenient way to collect data from several people simultaneously, focus groups explicitly use group interaction as part of the method. This means that instead of the researcher asking each person to respond to a question in turn, people are encouraged to talk to one another: asking questions, exchanging anecdotes and commenting on each other's experiences and points of view. The method is particularly useful for exploring people's knowledge and experiences and can be used to examine not only what people think, but also how they think, and why they think that way (Holloway and Wheeler, 2002). The size of a focus group is recommended to be between six and ten people (MacIntosh, 1993).

There are several key considerations in conducting a focus group (Morgan and Spanish, 1984). First, the focus group should examine a narrowly focused topic. Secondly, the topic should be of interest to both investigators and respondents. When the interest level is high, participants are more likely to provide concrete answers and highly detailed accounts of events (Merton and Kendall, 1946). Thirdly, in conducting the focus group, the emphasis needs to be on the interaction between group members rather than on the interaction between the interviewer and group members. The objective is to give the researcher an understanding of the participants' perspective on the topic of interest (Merton and Kendall, 1946).

Because the primary emphasis is on stimulating interaction among the participants, the researcher's role is not so much that of interviewer, as that of facilitator/moderator: guiding the direction of the respondents' comments so that the discussion does not stray too far from the research's established focus. It is recommended that each focus group have both a facilitator/moderator and also someone to record the discussion. The moderator is responsible for facilitating the group, encouraging quieter respondents to speak up, and for quietening the more talkative participants. If not dealt with directly, an opinionated individual can redirect the group's discussion. Asking participants to respond to such a person is often an effective way of balancing the group and eliciting responses from the majority. Whether the moderator chooses an indirect or a direct approach to leading the focus group, caution must be exercised in case the facilitator obtains results that reflect their own particular perspective or bias (Morgan, 1988), rather than reflecting that of the focus group.

3.1.1 Benefits of Focus Groups

Focus group discussions have several advantages. They are an excellent method for collecting qualitative data where participants are able to build upon one another's comments, stimulate thinking and discussion, and therefore generate ideas and breadth of discussion (Kreuger, 1988). They can produce high quality data because the focus group's moderator can respond to new issues as they arise. He/she can seek illustrations of relationships and linkages between questions, probe for clarification and solicit more detail (Morgan, 1997). Focus groups may aid in conceptual thinking and generation of hypotheses if the researcher is exploring a new area.

3.1.2 Focus groups limitations

A fundamental disadvantage of focus groups is their susceptibility to bias, because group and individual opinions can be swayed by dominant participants or by the moderator, (Kitzinger,

1994; 1995). In addition, control over the group discussion can be a problem and time can be lost on issues irrelevant to the topic if a discussion wanders from the original topic. In such situations, the data could be “messy”; therefore, it is imperative that moderators are skilled facilitators to overcome this potential setback.

Groups are often difficult to assemble and response rates can be a problem. A telephone or mail reminder to the participants regarding the time and place of the focus group is helpful. It is advisable to over-recruit by 20%, as some people may change their minds about participating or fail to turn up on the day of the discussion (Morgan, 1997).

One limitation of focus groups is that they can be difficult to arrange when potential participants are busy professionals. In this project, it was impossible to organise the relevant service providers for a focus group, and therefore semi-structured interviews were used instead.

3.2 Implementing the Research methods

To achieve the research objectives, two interview strategies were put in place:

- (i) two focus group interviews with East African women in Christchurch with FGM
- (ii) individual semi-structured interviews with selected service providers

3.2.1 Ethical issues

The research was reviewed and approved by the University of Canterbury Human Ethics Committee - approval number: URA/11/07/034 2011. The most important ethical issues in this research were to ensure non-coercive participation, properly informed consent, provision of effective opportunities to participate, as well as provision for the anonymity of individuals

and the confidentiality of their data. These are addressed in the description of the method, below.

3.2.2 Two focus group discussions with East African women in Christchurch who have undergone FGM

Two focus groups were set up with women from East African countries: Eritrea, Ethiopia, Somalia and Sudan. These countries are the origin of the majority African refugees in New Zealand.

As the study involved discussion of beliefs and personal attitudes towards FGM, and people living with FGM, the plan was for the group to explicitly encourage the women to talk to one another in the discussion, exchanging anecdotes and commenting on each other's experiences and points of view. The presence of diverse views was expected to decrease cultural anxiety through discussion of the impact of FGM on the health of women in Christchurch. Focus groups were expected to encourage and examine women's honest discussions of the events surrounding their experiences FGM related to maternity care (labour, birth, and the postpartum period) and the health providers' services and facilities.

a. Sample selection

- *Group A*: women with FGM from the East Africa aged 18-40 years with children born in New Zealand, or without children (7-10 Women)
- *Group B*: women with FGM aged 30-50 or older with children born anywhere (7-10 women).

It was accepted that more than two adults with FGM from the same family may be in a group.

The sample size was determined by the optimum size of focus groups (8-10 people) and availability of potential recruits was based on a purposive sampling of women who met the criteria.

b. Recruitment of participants

Recruitment of the sample for each focus group followed the procedure approved by the University of Canterbury Human Ethics committee using the following approved documents:

- information sheet and consent form English, version 2 dated 6 August 2011 (Appendix 1)
- information sheet and consent form Arabic, version 2 dated 6 August 2011
- interview guide for focus groups with women (Appendix 2)

As noted above the recruitment criteria included women 18 years or older, who were residents of Christchurch from FGM practising communities, and who were willing and able to commit to the research process.

Because of the sensitive nature of this project, recruitment of participants was undertaken by someone other than the researcher to ensure that no potential participant felt coerced to take part. With the approval of Canterbury Refugee Council (CRC), a female student social worker associated with the CRC approached women from East Africa known to the social worker and researcher as likely to have had FGM. This took place informally at community gatherings, e.g., at the Mosque, hair salons, henna parties, baby showers, and social evenings to seek their participation. All those taking part were required to be permanent residents in New Zealand. Information sheets and consent forms in both English and Arabic languages provided each woman with enough information for her to make an informed decision about whether or not to participate.

The information sheet also included details of the security offered to participants, including voluntary participation and freedom to withdraw at any time. Each of them understood that the information from the study may be published; but that contributions would be anonymised and all personal information was confidential. A leaflet from the Office of the Health and Disability Commissioner informing participants of their rights when taking part in research was attached. Consent forms were provided along with the information sheet (see Appendix 1).

c. Focus groups data collection.

At the start of the interview, the information sheet was again discussed and the consent forms signed. Interviews were conducted in a mixture of English, Arabic and Somali. The researcher and a recorder both spoke these languages allowing the participants to contribute to the discussion either their first language or English. An interpreter was also present. All the interviews were audiotaped.

Data collection was directed toward discovering “who” were the East African women living in Christchurch, “what” was their situation (living with consequences of FGM), and “how” FGM had shaped their health experiences. Data collection was based on discussion of a list of topics as detailed in Appendix 2. The researcher was seeking women's honest opinions of the events surrounding their health experiences related to FGM, e.g. antenatal care, labour, birth, and the postpartum period. The researcher moderated the discussions so that each person was encouraged to respond to questions, exchange anecdotes and comment on each other's experiences and points of view. In several instances the discussion was summarised by one of the women reporting on behalf of the group.

d. Focus group analysis

Qualitative content examination was the analysis strategy chosen for the first part of this analysis, because, as Altheide (1987) and Morgan (1997) both note, it allows an organised summary of the informational contents of the data gathered. The study was guided by the structure of the literature review in which the sequential stages of women's health experiences after FGM were reported. The analysis followed a narrative form that matched the typical reproductive health sequence, reflecting the experiences of many of the women. In addition, several typical partial case histories were developed (vignettes), based on the individual experiences of women (with details checked later with each individual) but modified to ensure anonymity. A thematic analysis was also undertaken of the focus group interviews using the approach recommended by Thomas et al. (2004).

3.2.3 Interviews with service providers

There are few New Zealand health providers experienced in looking after the health of women from East African countries and health providers are not always able to offer access to health issues trained interpreters for these women.

Semi-structured interview questions were used, because it proved too difficult to get the relevant health providers together in the same place at the same time. Two interview sessions took place, one with two providers based at the same workplace and a second one with an individual provider. The health professionals involved included a general practitioner, a Registered Nurse, and a health social worker.

Health providers were recruited adhering to the procedure approved by the University of Canterbury Human Ethics committee described in the following approved documents:

- information sheet and consent form; interview guide for health service providers (see Appendix 3)

- interview guide for health service provider (see Appendix 4).

Interviews were audiotaped and transcribed and then checked with the interviewees. A thematic analysis was undertaken of the transcripts.

3.3 Positioning the researcher in the research process

The researcher has worked with marginalised refugee and migrant women resettling in Christchurch for the last two decades. Previous roles have included work as a multilingual, cultural advocate and health promoter in several organisations: the Christchurch Resettlement Support Centre, the Refugee and Migrants Centre, and New Zealand AIDS Foundation. Originally from Somalia and trained as a medical doctor, who has worked in several East African countries and survived war there, the researcher's focus has been on the clinical experiences of FGM women in New Zealand and how these have been managed.

With the shared war experiences, culture, religion, music, dancing and poetry there were many connections among the East African women in the focus group. This generated trust and confidence during the focus group discussions with enthusiastic dialogue exchanges in different languages. Working with the interpreter the researcher/moderator's responsibility was to guide the direction of the respondents' comments so the discussions did not stray far off topic. The moderator/researcher, and later interviewer, had to listen closely and take notes to identify any unspoken themes, to be open to the needs of the person expressing the views and pick up clues as to the person's real need. "Listening" was required, not only with the ears, but also with the eyes and other senses.

After the focus group discussions were completed, the audiotapes were transcribed, clarification sought from participants, individual stories recorded and then the material was analysed into a series of themes. In addition, the researcher was seeking, if possible, to

establish the reasons for individual's thinking and what led to it. This approach has helped to minimise information and observation bias in the group discussion and at follow-up meetings, so that interaction between group members could aid understanding of the participants' perspectives of their health experiences.

Chapter 4: Results

4 Introduction

This chapter reports on the discussions of the two focus groups of East African women who have FGM, and the separate interviews with health service providers. In the early part of the chapter the East African women's experiences are discussed, addressing their experiences of FGM, of General Practitioner (GP) services, and Obstetric and Gynaecological (O&G) services. As well as presenting their experiences across a range of health service sectors, and for various health issues, their experiences are presented in thematic format. In the latter part of the chapter the interviews with the health service providers are reported in thematic format.

The focus group participants (20 women) all originally came from East Africa and all now hold New Zealand Permanent Resident status or New Zealand Citizenship, have lived in Christchurch more than five years and were aged 21-65 years. Seventeen of the 20 had children who were born in New Zealand or overseas. At least 35 children had been born overseas but not all of those children survived; some died in infancy and some in the civil war. A total of 21 children were born in New Zealand, all at Christchurch Women's Hospital. Seven of the 20 women who had given birth had their first childbirth experience in New Zealand. Five of them had children only in their home country of Eritrea, Ethiopia, Somalia or Sudan. The remaining five women gave birth in both their home country and in New Zealand.

Details of the health services experiences of women are presented both through direct quotations and also through partial case histories. These are presented as case "vignettes" because the community is small and anonymity could not be preserved if a normal full case

history were given. To further preserve the anonymity of individuals, personal details (such as age or number of children) are largely removed, and the case vignettes are numbered consecutively so that they are not linked to any individual participant.

4.1 The experience of FGM and de-infibulation

This first section outlines the women's experience of FGM and the general problems that it causes in terms of pain, urinary tract infections (UTIs), PID, sexual intercourse, and infertility.

4.1.1 The experience of FGM

All of the women said that they had experienced both immediate and long-term complications of FGM: type III for Somalis, and FGM types I and II for the other East African women. All of the women experienced severe pain.

One women on behalf of focus group stressed

“There were severe pains during cutting genital tissue, such as cutting the sensitive nerves without anaesthesia. The healing period were continuing painful too”.

The procedure for type III FGM is more extensive and of greater duration than for FGM types I and II. Both the intensity and duration of pain during the procedure appears to be greater than for types I and II. The healing period for type III is also extended and accompanied by greater difficulties with immediate labial adhesion and widespread closing of the vaginal opening. All the women shared anxieties about passing urine because of the painful burning sensation of urine on the raw wound.

“We never forget painful difficulties in passing urine and faeces through swelling raw wound during the early days following the FGM procedure. The pain, shock and the

use of physical force by those performing the procedure are mentioned as reasons why many women describe female genital mutilation as a traumatic event".

As noted in Chapter II, concerns related to FGM types II and III in the long term include UTIs and PIDs. These occur when a flap of skin obstructs the urethral channel after the FGM procedure and urine then flows into the vagina from where it drains slowly and provides a source of urinary stagnation that may lead to recurrent UTIs. This obstruction also prevents appropriate vaginal cleanliness and menstrual drainage which also contributes to recurrent UTIs and may also lead to PIDs.

Most of women commented

"We have experienced during childhood and before de-infibulation slow urinary stream, straining urine retention and sometimes urinary tract infection".

Such experiences can last for hours or days, because of the damage to, and associated inflammation in, the surrounding tissues.

In marriage, without or before de-infibulation, sexual intercourse can be most painful.

One woman spoke for the Somali participants:

We suffered a lot during our honeymoon, pain we could not describe, it was dreadful.

For some couples it could take several months to achieve penetration, or the woman might conceive without penetration. The barrier to penetration was the presence of scar tissue resulting from FGM type II or III.

One woman said:

A major problem during first sexual intercourse is the small opening left in the scar tissue resulting from FGM types II or III. The opening may be forcibly expanded during intercourse. This painful process does not always result in full penetration and

causes a poor young girl to suffer. The opening must be made either at the time of marriage, or earlier, to allow intercourse to take place and the couple needs counselling.

For some infertility can be an important consequence of FGM because pelvic infection may leave a woman infertile. In Africa women who cannot not conceive and carry a pregnancy have been divorced or the husband has neglected her and taken another wife who can produce children.

Several women said,

“We become infertile and our husbands divorced us, or neglected us, or they marry other women, because of that now we are single”

Those who have pelvic infections but who do conceive are likely to have problems during pregnancy, and then also difficulty in childbirth, because of pelvic scarring.

4.1.2 The experience of de-infibulation

As part of the focus group discussions women described their experiences of de-infibulation, the procedure that opens a vagina that has been partially closed by FGM. Women find it shameful to ask for de-infibulation as the existence of the infibulation is considered a sign of virginity. Culturally, it is the task of the bridegroom to dilate gradually the vaginal opening of his bride to permit penile access.

One woman on behalf of East African women said:

Even though we had FGM type II or III, had a small vaginal opening and were virgins, we did not ask for de-infibulations before marriage because that is shameful in our culture. Most of us who have FGM type I or II had problems with penetration following marriage. The remaining opening was, for some of us, forcibly extended

during intercourse and we experienced a lot of pain so we did not always get full penetration.

Another woman spoke on behalf of the Somali women present:

We had FGM type III and a very restricted vaginal opening and no one has had de-infibulations. We are surprised that de-infibulation is available as a surgical procedure at Christchurch Women's Hospital.

Another woman declared:

I wish I had known there was a de-infibulation surgical procedure available in New Zealand. I was married in Christchurch and, until now, I have suffered pain during or after sexual intercourse. I have felt without support, and helpless.

Most Somali women in the interview were born in south Somalia where it is shameful to ask for de-infibulation.

4.1.3 Contact with General Practitioners (GPs) in New Zealand

The women from both focus groups agreed that they all felt shame in talking about FGM with their General Practitioner (GP), that there was not enough time to talk about it with their doctor and it often proved too embarrassing or difficult even when an interpreter was present.

One woman said:

I talked my doctor about FGM, but in fact, she spoke only of symptoms: I complained about pelvic pain and vaginal discharge, so the doctor prescribed blood tests, a urine test and cervical screening.

Another woman on behalf of all women present emphasised that:

New Zealand doctors do not ask about FGM. The time allowed for the consultation is very limited, and there is poor communication.

One woman reported from the group discussion:

We do not have a support person or interpreter, and become frustrated in communicating with the doctors. Sometimes doctors use medical terms, which are very difficult to follow, so we carry on without understanding or we make assumptions.

Another woman stated:

Some women prefer to go to the pharmacy and buy some medication, but women from Eastern African countries such as Eritrea and Ethiopia use an interpreter service, because their English is poor. They came from refugee camps and they have lived fewer years in New Zealand than Somali women.

One woman reported:

We agreed that nobody talks about FGM. Even when a support person or interpreters are available, women report that they do not talk about FGM, because of the time it takes and the shame.

When the researcher asked the women about conception methods or contraception control it was clear that they had no understanding of either matter. The researcher then explained that conception occurs when the egg of the woman is fertilised in the fallopian tube by the man's sperm, the egg then moves down the tube to implant in the womb. Contraception is the deliberate use of either artificial or natural means to prevent the egg becoming fertilised.

One woman, on behalf of all participants said:

We do not understand either conception processes or the methods of contraception and are reluctant to use them. The main reason we have for not wanting to use them is that we do not understand because we are unable to communicate well. This is culturally new to us and we do not know what to do.

Everyone agreed that:

We did not have sufficient knowledge about contraception or conception and were very busy settling into the daily life of a new country. We had problems with reading and writing in English.

One woman said:

I never went school.

Another woman reported:

I had had no counselling about FGM, no information about lubrication and sensitivity to pain or the discomfort of vaginal or pelvic examinations.

4.1.4 Experience of Gynaecological Services

Some women have had miscarriages in New Zealand and subsequently had dilatation and curettage (D&C) under anaesthesia. However, several women have had incomplete miscarriages.

The following vignette illustrates the process and hospital experience of one woman as she explained it to the focus group. She said that it had been a good health service experience for her.

Vignette 1

A woman in her later thirties described her symptoms:

I was in the tenth week of pregnancy. I had intense cramps and lower pelvic pain, vaginal bleeding and was told that some tissues had passed from my uterus into the vagina. Some tissues remained inside my uterus. The cervix remained open because of uterine contractions. My GP referred me to Christchurch Women's Hospital Gynaecological Emergency Services with medical notes. I was told that the mostly likely diagnosis was an incomplete miscarriage, which would be treated by D&C.

The woman was taken to the operating theatre where she had an epidural anaesthesia and the uterus was emptied using sponge forceps followed by a careful curettage. Towards end of the curettage, an injection of Ergometrine was given intravenously and the tissues expelled were sent for histological analysis.

Staff explained the procedures to her before her operation and she did not ask for an interpreter. She spoke only simple English and asked the researcher to assist her.

Vignette 2

Another woman reported a positive experience with the hospital gynaecology service. Her GP referred her to Christchurch Women's Hospital Gynaecological Emergency Services with her medical notes. The woman with FGM type III had diabetes and was complaining of postmenopausal vaginal bleeding. Prior to menopause in her fifties, she had had irregular periods and had experienced postpartum haemorrhage. She was not on oestrogen replacement therapy. She was admitted to hospital. She had numerous risk factors for endometrial cancer including obesity, diabetes, and irregular menses, she was not on hormonal therapy, but was complaining of vaginal bleeding with atrophic vaginitis. She had a biopsy, but did not know whether there had been a direct visualisation of the endometrial cavity for other conditions.

She had a bilingual support person from CRS and went twice a week to a women-only exercise group, which she enjoyed. She has complex health problems and she said that she

needed to understand her health issues better. However, she was satisfied with her health service experience.

Vignette 3

Another woman, some weeks after losing a pregnancy developed excessive and irregular bleeding, which led to anaemia. Iron tablets were prescribed and her iron levels were restored. She was then fitted with a Mirena intra-uterine contraceptive device (IUD/ IUCD) to control the bleeding. Her doctor taught her how to check each month, immediately after each menstrual period, that the string hanging through the vaginal canal was in place. She did not fully understand this process and asked the researcher for advice. Then after four months, the IUD was expelled from inside her uterus without any side effects and her periods became regular. After a few years her periods once more became irregular but she now no longer uses contraceptives. She viewed her experience of the health services as positive.

4.1.5 Ectopic pregnancy and complications

Ectopic pregnancy usually occurs in the uterine fallopian tube when the passage of the fertilised egg through the uterine tube is halted. The most likely cause among East African women with FGM may be decreased muscle tone in the uterine tube or abnormal anatomy, including scarring from PID or from FGM, previous uterine tube surgery, or previous ectopic pregnancy.

Vignette 4

One woman described her ectopic pregnancy:

I was only 12 weeks into my first pregnancy, everything had been normal but then I felt mild lower abdominal discomfort. After few weeks I had severe lower abdominal pain, and collapsed with a weak pulse and falling blood pressure. My husband called an ambulance and I went to the Emergency Department at the Christchurch Women's Hospital. A blood test showed that my risk of ectopic pregnancy was very high. An

emergency laparoscopy revealed that I had an ectopic pregnancy. I was not quite sure whether the tube had ruptured. Overall, I had good care, but I did not understand the condition, so I felt unprepared. Neither my husband nor I were able to speak English well and the hospital did not provide an interpreter. I was frightened and memories of the pain of FGM and worries about what it might mean for the present situation confused me and made me even more afraid. However, the overall care provided to me as a patient in the hospital was good.

4.1.6 Experience of antenatal care

When asked if they understood the purpose of antenatal care, most of the women said they did not. The researcher explained that antenatal care is to ensure a healthy mother and baby and a safe delivery. She also explained that GPs provide the first ten weeks of antenatal care, and then the GP refers the woman to either Christchurch Women's Hospital or a community care midwife for the rest of the antenatal care.

Women have approximately 14 visits to a special maternity clinic and a few visits to the hospital as an outpatient during their pregnancy. Most of the women who have had childbirth both in New Zealand and outside New Zealand agreed that they received good antenatal care in New Zealand. They reported that they all had an antenatal ultrasound scan at 16-20 weeks of pregnancy and various laboratory tests.

When asked whether their midwife had discussed FGM and de-infibulation with them, some women replied, *"Yes, but she did not undertake a physical examination"*. As women with FGM type II or III are likely to have trouble with childbirth due to a scarred vaginal opening, and therefore it is crucial that they are carefully inspected by the midwife.

A number of women had had complex pregnancy histories. Vignettes 5 and 6 below are examples.

Vignette 5

During her first pregnancy one woman experienced severe morning sickness with nausea and vomiting, becoming dehydrated. She was admitted to hospital and intravenous treatment was started urgently to avoid possible damage to her liver and kidneys. Oral feeding was not allowed. Hydration and electrolyte balance were corrected and fluid intake and output (urine) was recorded. Blood pressure monitoring was instituted and she was put on a special diet throughout the remainder of the pregnancy. Even though she had good antenatal care, at 38 weeks she developed generalised pre-eclampsia symptoms of raised blood pressure, headaches, visual disturbances, dyspnoea, chest pain, reflux, face/hand swelling and proteinuria. The baby was delivered urgently by caesarean section to save the lives of both mother and baby.

Vignette 6

A woman in her second pregnancy that had gone smoothly and without complication felt that she had had good antenatal care.

She explained:

My blood pressure and urine tests were good. At 40 weeks, labour was induced because I had my membrane ruptured prematurely. In the middle of labour the baby became stressed, my blood pressure rose and I had to have a caesarean section.

Two women experienced gestational diabetes at 26 to 28 weeks with FGM type III. They received diet control therapy and insulin therapy and were followed up well. They had labour induced at 38 or 39 weeks to avoid the risk of a very large baby and a prolonged second stage of labour. Even though their midwives asked about their FGM, they had not been de-infibulated during antenatal care and did not know that restoring the scar site to a state of infibulation is illegal in New Zealand. Details of one of the cases are set out below.

Vignette 7

During her second pregnancy, a woman was referred by her GP to Christchurch Women's Hospital antenatal care where she met the midwife who had looked after her for her first birth. Screening for gestational diabetes at 26 weeks proved positive and she started diet control and oral insulin therapy. She remained under specialist care with regular monitoring of the baby's weight because of the likelihood of large baby should the pregnancy progress beyond 39 weeks.

She said:

I disliked ultrasounds but it was explained that it does not harm the baby and could prevent antenatal complications if my pregnancy went beyond 39 weeks. Even though I had an interpreter during antenatal care, I found it difficult to understand all the medical terms and I became anxious because I was afraid of complications because of my FGM during labour. My midwife told me that I would have an induced labour at 37-38 weeks of pregnancy.

4.1.7 Experiences during and following childbirth

Most East African women who have FGM type II or III have a number of pregnancy-related risk factors including: communication problems, postpartum infection, shame and fear related to the complications caused by FGM, reacting to negative thoughts, and confusion during labour. Episiotomies are commonly performed on women with FGM to allow the baby move forward more easily. These are painful and because of this, women are often reluctant to push in the second stage of labour.

A woman's delivery history can indicate to health professionals whether she is likely to have persistent problems, such as delayed labour. It is important to find out whether re-suturing has taken place following an earlier delivery. In this respect, there are major variations among

communities, even in the same country. Repeated cutting and re-suturing (“de- infibulation” and “re-infibulation”) leave extensive scarring that is often unstable.

Vignette 8

The woman commented:

At last my baby was born and I had large two episiotomies, which were re-stitched. However, I was not sure that I had been re-infibulated. My midwife and an interpreter supported me a lot during labour and afterwards.

Vignette 9

For one woman, a specialist attended during childbirth who advised the midwife to do three episiotomy cuts when the baby became fully engaged through the vaginal opening. Even though mother and baby were well looked after and the woman reported positive experiences, she did not have an interpreter during childbirth and could not communicate well.

The woman reported:

Owing to poor language skills and improper attitudes there were communication problems between the caregiver and me.

The providers spoke to me using many health terms, but I did not know what they meant, I did not know about the functioning of a healthy reproductive system. In the past, I wanted to hire my own teacher and learn English. However, because I am on a low income I am not able to seek that kind of help.

Vignette 10

A young woman with FGM type III, expecting her first baby experienced induced labour at 42-43 weeks pregnancy.

She said:

I had access to an interpreter. Even though my midwife had discussed FGM during antenatal care, she did not do a de-infibulation this time. During childbirth my midwife called a male obstetrician. I felt shame because several people (two midwives, the male doctor and interpreter) were there.

I was worrying and fearful because I have FGM type III and believe that New Zealand midwives have insufficient experience to take care of women with FGM type III. My fears led to confusion during labour. Although I had a good interpreter, I still had communication problems. I was missing the meaning of words even in my own language because I do not understand how the reproductive system works. I had a prolonged labour of more than 12 hours, which was stressful and exhausting. I was sucking gas and became very muddled; I could not control my actions or myself during labour.

Vignette 11

Another woman, for her second pregnancy was referred by her GP to Christchurch Women's Hospital antenatal care. She described her experience of labour and childbirth:

I became anxious and prayed to God to save my child and me from premature labour. Fortunately, I went into labour naturally during the 37th week of my pregnancy. The first stage of labour started in the middle of the night, I called my midwife and a Somali family took care of my first baby.

There were no interpreters available to support me or to translate my words and I became very anxious, fearing complications of my FGM type III, and afraid I would lose my baby. I had a lot of pain during the contractions. The midwife tried to support me; she indicated that I should suck gas for pain relief. I refused to suck the gas because I had over-used gas during my first birth and had felt that I was going crazy.

I refused even though I was in a prolonged labour and was afraid for both the baby and me. I thank God the childbirth went well; my baby was born a normal weight and a good paediatric team took care of my new baby. After my midwife restored my two episiotomies, I felt better than after my first birth experience. Following childbirth, I had good postpartum care and the paediatric team looked after my baby. I am not diabetic now.

Vignette 12

Many women with FGM have one or more episiotomies so that the baby can move forward during the second stage of labour.

An episiotomy is a planned, surgical incision on the perineum, the rear vaginal wall or both during second stage of labour. The incision is performed under local anaesthetic and is closed with sutures after delivery.

Episiotomies and perineal tears are by far the most common complications of childbirth for women with FGM. As discussed in Chapter Two, there is substantial evidence to show that women with FGM suffer more perineal damage because of delivery than those without FGM. Pain from anterior episiotomy of women with type III or II may result in “secondary inertia”, meaning women with FGM are reluctant to push in the second stage of labour.

One woman reported that she had de-infibulation with two episiotomies in order that the baby’s head could have sufficient space to move forward. Only the two episiotomies were closed, she was not re-infibulated. She lost a lot of blood, but she did not know the reason. She felt her midwife was a very caring and understanding person.

Most of the women who have had babies in Christchurch Women’s Hospital agreed they have been looked after very well.

One of the participants said:

We had good management in the immediate post-delivery period all the time.

4.1.8 Postpartum bleeding or haemorrhage

Postpartum bleeding is a blood loss of greater than 1500ml with a vaginal delivery. The most common cause of postpartum haemorrhage is loss of muscle tone in the uterus.

Vignette 14

A young woman, in her first pregnancy, described her first childbirth in detail:

My first pregnancy was an induced labour. I was in active labour (my cervix was dilated three or four centimetres) when my midwife performed an artificial rupture of the membrane. The baby's head had engaged but it was still very high. In order to monitor the baby's heartbeat, a scalp electrode was placed on the baby's head, so the baby's heartbeat could be monitored. My second stage of labour took longer than normal and my baby became tired then exhausted. When I was fully dilated my baby's head engaged, but I could not push well and I became disoriented. The doctor used vacuum extraction on the baby in order to save both of us. A paediatric team supported my baby ensuring he started to breathe. I had postpartum bleeding. My doctor very carefully inspected my genital tract for lacerations. I lost a lot of blood from my vagina. My midwife and doctor massaged my lower abdomen and gave me an intravenous infusion of salt water and broad-spectrum antibiotics. Fortunately, I was not severely anaemic and soon stabilised. Later, I developed a severe fever, so the doctor did a swab test on my vaginal discharge and I was given intravenous antibiotics to avoid infection.

Vignette 15

Another participant reported a haemorrhage after childbirth:

My last childbirth was via an induced labour because I was overdue, at more than 42 weeks. I had an interpreter, and the doctor and midwife explained all the procedures of my labour. After a long labour, I was exhausted and confused. At last, after 10 hours of labour I became fully dilated and delivered the baby. My baby was very stressed and was taken to the paediatric ward from the postpartum ward. After a few hours, a midwife or nurse asked me to go to the paediatric ward. I told her I was not feeling well, but she wanted me to go with her and feed the baby. She put the baby into my lap and the baby started to suck my breast. Within one or two minutes, I felt unwell and started bleeding. I put my baby on the bed and rang the emergency bell before losing consciousness. I lost a lot of blood and needed a transfusion of two litres of blood.

Vignette 16

Another woman who had already had several children noted

I had severe nausea and was hospitalised. At 39 weeks, I had normal labour vaginal delivery, but I developed serious potentially life-threatening postpartum fever within the first 24 hours. The hospital provided prompt and effective treatment with intensive care.

4.2 Thematic analysis of East African women's views

The previous sections reported the narrative of women's clinical experiences. A thematic analysis of this data, as outlined would be undertaken (3.3.3d), identifies four themes:

- satisfaction with clinical care
- experience of de-infibulation
- barriers to knowledge among women about the reproductive system
- culture and communication

4.2.1 Theme one: Satisfaction with clinical care

All the women agreed that the midwifery services were supportive and caring with a calming environment during postnatal care. Some reported positive experiences with hospital gynaecology services and good levels of support from CRS. Most of the women who have given birth both in New Zealand and overseas agreed they have had good antenatal care in New Zealand. They reported that they all had an antenatal ultrasound scan at 16-20 weeks of pregnancy and laboratory tests such as: complete blood count, urine culture, blood type analysis for RH factor, tests for hepatitis B surface antigen and HIV, as well as screening for gestational diabetes at 26 to 28 weeks.

Most of the women who had babies in Christchurch agreed they have been looked after very well.

Examples of comments made by the women include:

I had a very good team who were very caring, a lovely support to my family and me and an interpreter was available during labour. However, we still need culturally appropriate education, knowledge of sexual health and child birth, counselling and education, in particular there needs to be a focus on minimising the fear of episiotomies during labour and acquainting women with the hospital culture in their new country.

We had a very good team who were very caring with a lovely support to the patient and her family, and an interpreter was available during labour. We had good management of immediate post-delivery all the time.

4.2.2 Theme two: Experience of de-infibulation

Women spoke about de-infibulation occurring on three separate occasions: among young girls, during antenatal care and during childbirth. With respect to young girls, the women

understood that in New Zealand there are services available to support young migrant girls with FGM to prevent pelvic infections, urinary infections, painful menstruation and ease first sexual intercourse. One woman commented:

I wish I had known there was a de-infibulation surgical procedure available in New Zealand. I was married in Christchurch and I felt without support and helpless. Until now I have suffered pain during or after sexual intercourse.

Another said:

We suffered a lot during our honeymoon with pain that we cannot describe, it was dreadful.

Young girls or their parents can ask New Zealand GPs for de-infibulation and this is occurring among women with higher levels of education.

One woman on behalf of the East African women said:

Even though we had FGM type I or II and had a small vaginal opening and were virgins, we did not ask for de-infibulations before marriage as this is shameful in our culture. Most of us have FGM type I, II or III and we have all had problems with penetration following marriage. Sexual intercourse can forcibly expand the remaining opening – a painful process that does not always result in full penetration.

With respect to antenatal care, some women explained that midwives discussed FGM with them during that time. When asked whether they had had de-infibulation during antenatal care they all said that "no", even though it had been discussed at the time. The problem of infibulation is neither well recognised nor acted upon because midwives do not normally do vaginal examinations of these women during antenatal care. Some focus group participants noted that although the midwives discussed FGM, they did not undertake a physical examination, adding that:

During childbirth, women with FGM type II or III are likely to have trouble with childbirth due to a scarred vaginal opening; it is good for the midwife to inspect them during antenatal care.

In labour, women reported that the second stage was very long because of FGM scarring and they were afraid of their genitals tearing. Lack of de-infibulation can create problems for the mother and the new-born baby, who might fail to initiate and sustain breathing at birth, thus requiring resuscitation. The direct effects to the mother of a prolonged period with the baby's head in the vagina are an increased risk of perineal injury and associated postpartum haemorrhage.

Some women said that:

Sometimes this reminds them of their childhood anxiety about FGM, and this worry projects itself into the present situation, causing confusion and loss of energy. The lack of counselling in antenatal care regarding the possibility de-infibulation during childbirth was very worrying for some women.

One woman said

I was so frightened for my circumcision and childbirth as cuts and tears to the woman are known to be the most common complications. I felt that women with FGM suffer more cuts and tears because of delivery than those without FGM.

Another woman remembered that that the midwife coached her through the breathing and pushing of the second stage of labour, then:

Finally, the baby became fully engaged into my vaginal canal and started to move forwards. The midwife did a de-infibulation with two cuts so that the baby's head would have sufficient space to move forward.

4.2.3 Theme Three: Barriers to knowledge among women about the reproductive system

Women pointed out that their own lack of education and lack of English meant that they did not understand information in pamphlets or much of the information given in antenatal classes. They were unable to understand or follow medical terms relating to the reproductive system during consultations for contraception, cervical screening, during antenatal care or childbirth, even with the presence of interpreter.

Women report that they do not talk to health professionals about FGM, because of the time it takes, the language and cultural barriers to discussing it and a lack of health advocates and counselling. There are communication problems, which result in anxiety, depression and difficulties with resettlement.

When the researcher asked the women about conception control, they reported that they had very little knowledge of contraception and its consequences, such as the benefits and weaknesses of particular types of contraception. After the researcher explained some of the methods of contraception and family planning some women pointed out that they had no knowledge or awareness of many of these methods of contraception, such as long-acting reversible contraception (LARC) methods and emergency hormonal contraception. They stressed fear of vaginal examinations anticipating that these would be painful. They pointed out that problems are multi-dimensional with physical health problems sitting alongside the emotional difficulties of settling in a new country and the resulting social and cultural adjustments.

One woman, on behalf of all participants, said:

We did not understand the methods of conception or contraception and were reluctant to use them. The main reason for not wanting to use them was that they could not communicate well, and so they did not understand. It culturally new to them and they

did not know what to do. We did not have sufficient knowledge about contraception and had concerns about settling in a new country and the associated difficulties of a new daily life. In addition, we had problems with reading and writing in the English language.

With respect to educational levels and literacy, one woman said she had never been to school.

Another woman reported:

I had had no counselling about FGM, including information about lubrication, sensitivity to pain and the discomfort of vaginal or pelvic examination.

4.2.4 Theme four: Culture and communication

Barriers identified above by focus group participants include:

- a lack of understanding of the meaning of medical terms
- no knowledge about a healthy reproductive system, which causes them problems during consultations with health providers

Women with FGM report they rarely speak directly about the psychosocial health symptoms of FGM, but tend to present with some physical complaint. Because many of them do not know how to own their feelings they spend a lot of time blaming other things; that, of course, continues the cycle of disempowerment. Health providers do not understand the support needs of women with FGM, with their vulnerability, low self-esteem, and fear or anxiety.

One woman on behalf of focus group participants stressed:

New Zealand health providers do not ask about FGM. The time allowed for the consultation is very limited. We do not have a support person or qualified interpreter of FGM present, and we became frustrated trying to communicate with the health providers. Sometimes health providers use many medical terms that are very difficult

to follow, so we carry on without understanding or we make assumptions that might not be correct.

Most of women in the focus group agreed:

They all felt shame in talking with their health providers about FGM, that there was not enough time to talk GP about it, and even if the situation permitted, it was often too uncomfortable or difficult when an interpreter was present.

Women in the focus groups were clear that New Zealand doctors rarely ask about FGM. Christchurch has good interpreter services, but these are not adequate to respond to the number of women resettling in Christchurch from countries that practise FGM.

One woman on behalf of all the women emphasised that:

Women with all FGM types need health care support workers with appropriate knowledge and skills during health provider consultations and during labour to manage the physical, psychosocial and psychological health problems that result from FGM.

A number of women said that sometimes this reminds them of their childhood anxiety about FGM. These anxieties project forward into the childbirth situation causing the women become confused and depressed. Another concern for the women is the lack of counselling during antenatal care regarding the possibility of de-infibulation during childbirth.

4.3 Thematic analysis of health providers' views

The previous sections reported on the experience of women with FGM. This section reports on the views of three health providers. In order to maintain their anonymity, their professional allegiance is not identified. Their interview responses have been organised into

three themes: health providers' experiences, the knowledge gap, and culture and communication.

4.3.1 Theme one: health providers' experiences

All health providers have, at one time or another had the experience of not asking if an East African client has experienced FGM or not. They were not always aware that their female clients could be circumcised, and that early acknowledgement of the circumcision may help prevent complications and assist in the management of physical, psychosocial, and mental health problems.

One health provider stated:

I had never heard of FGM from my clients or other health providers. There is silence about FGM.

Two of the health professionals who look after refugees and migrants reported that around a decade ago they used to see more refugee women with health complications of FGM, such as pelvic infection, childbirth issues, and problems of first sexual intercourse. However, the health professionals also said that the formal education for health providers was not sufficient to ensure excellent care and management of women who have FGM type II and III.

We do not see them now, but the main clinical symptoms were difficulties in childbirth and menstruation, urinary tract infection symptoms, problems in initial sexual intercourse and general embarrassment.

The services have improved over the last decade and include a formal interpreter service (not a family member), better funding for interpreters and better education for midwives and GPs. However, there is still ignorance among health professionals about FGM.

4.3.2 Theme two: knowledge gap

The health providers agreed there is insufficient formal education for health professionals regarding the care and management of women who have FGM. This topic has not appeared in health professional curricula in the past. In addition, there is no education about FGM in on-going professional development so that health workers may acquire the necessary knowledge about FGM. They also stressed the need to improve the capacity for dealing with FGM related complications:

The main barriers to effective service provision are the ignorance of health professionals about FGM, funding limitations and little awareness of the importance of using female health providers as opposed to males.

Providers commented that the professionals might lack the necessary knowledge and skills to enable them to help circumcised women effectively. One provider suggested that additional professional training might contribute to cultural social change, ultimately promoting the abandonment of FGM among affected communities.

Better understanding includes education about the culture surrounding this complex issue. It is most important to reach and empower communities through education and understanding.

Health providers reported there is a lack of relevant information and education resources available to either health providers, or clients in their own languages. Educating health providers, providing support services (such as counselling sessions) for clients will help to reduce the stigma of FGM and the silence surrounding it.

Better services are available in Auckland, which could provide a model for Christchurch. The service providers noted that introducing these services will require increased funding for education resources, to support affected women in FGM communities and support their

health service providers. Initiating research to underpin best practice among health service providers will also require additional funding.

4.3.3 Theme three: culture and communication

Health providers stated that there is a vital obligation to develop knowledge about FGM cultures and ways in which women from these cultures communicate. Some clients are conscious that the symptoms these women are presenting with are not the real cause of their problems, but women with FGM are too shy to talk directly; they need more confidence and to know that they will be heard. They attend the clinic hopeful that the health care provider will be competent to support them. One provider said that women with FGM need to be “*heard and loved*”.

Providers suggested that prospective research could assess both clinical outcomes and the effectiveness of communication between health provider and client. The providers also indicated the importance of understanding the feelings and emotions of the clients and encouraging them to be open and discuss what they need. One provider noted that in Auckland there is a special Well Women’s Clinic for East African and other women with FGM. The clinic offers special advice, support, counselling, and de-infibulation. Such a clinic could take referrals from health professionals and directly from women themselves, thus improving access to services for FGM women.

Education efforts need to be two pronged. There needs to be a focus on both service providers and FGM communities.

4.4 Summary

This chapter has presented the results of focus groups with East African women with FGM and interviews with health providers. They reported their experiences with clinical services

including both immediate and long-term complications of FGM. It also reported four themes from the focus group discussions. All comments relating to individual themes were identified and listed under each theme: satisfaction with clinical care; experience of de-infibulation; barriers to knowledge among women about the reproductive system; culture and communication. Three themes emerged from interviews with the three health professionals, relating to their experiences, the knowledge gap and culture and communication.

Chapter 5: Discussion

5 Introduction

As explained in Chapter 1, FGM affects 100–140 million women and girls worldwide (UN, 2009) across 28 countries in Africa Asia and Middle East FGM, with 3 million girls and women remaining at risk of the procedure each year (UNCEE 1997). Prevalence rates vary from 5% (Uganda) to 90% or higher in Egypt, Eritrea, Mali and Sudan, and Somalia (Rahman and Toubia, 2000).

Because of civil war there are currently thousands African women with FGM have immigrated into western countries round the world; some of them have resettled in New Zealand, and brought with them many traditional practices. Because of migration to other parts of the world, FGM has to be addressed in new social, cultural and health system settings. The purpose of this research was to understand the situation of both Christchurch women with FGM and their health providers, to increase knowledge about FGM and ensure improved health services for women with this condition. Central to this is the acknowledgement, well supported by the research reviewed in chapter two, that improved acknowledgement needs of patient with FGM, and provision of support they want is vital if growth is to be made in addressing the increasing personal and societal burden of women with FGM.

5.1 Research process

This research investigated the impact of FGM on the health and well-being of refugee and migrant women living in Christchurch, New Zealand. This study set out to illuminate the inter-relationships and communication between East African women with FGM and their

health providers. Data was collected through two focus groups of women with FGM and interviews with three health providers.

Key to this research process was the desire to hear the voices of women describing their health service experiences. This was made possible by the choice of focus groups for data collection among East African women living Christchurch. The focus groups were effective for this purpose for three reasons. There were already strong connections among the participants with the mutual experience of war, shared experiences of FGM, and common cultural and religious experiences. Second, the women felt safe in the environment because they had a high level of confidence in the researcher. The researcher explains:

"I survived war myself and have a passion to work with these women. In addition that the East African women are all connected in diverse ways through languages, culture, religion, music dancing and poetry including FGM. Therefore, there were trust and confidence during focus group discussion. I was listening and taking notes to hear behind their words, to be open the need the person expressing views and I was collecting clues and marks to a person's real requirements. I have been listening with my eyes and my feeling and senses."

Third, because the women felt safe and trusted each other, they were able to present some common views and speak for each other when necessary, for example, when their language skills or emotion made it difficult to express themselves.

5.2 Qualitative rigour

The research was able to maintain qualitative rigour by addressing the four mechanisms of trustworthiness that Thomas and Magilvy (2011) identify as crucial to qualitative research: credibility, transferability, dependability, and confirmability.

Credibility is ensured when the research presents "an accurate description of interpretation of human experience that people who also shared the same experience would immediately recognise" (Kreftig, 1991). The researcher spent much time listening to the women talking on the recording and then writing their stories, observing and following their energy flow in order to reflect their voices. In this way observation bias was minimised in the group discussion and follow-up meetings so that the interaction between group members became most important in revealing participants' perspectives on FGM. The credibility of qualitative research depends on the capability and effort of the researcher (Golafshani 2003), and in this case this was secured by the time spent with the transcripts and opportunities for follow-up clarification, and by using the words of the participants directly.

Transferability of the research has been enhanced by the explicit description of the sample, and the history of the women in terms of FGM and their medical stories. While carefully maintaining anonymity, the specific nature of the findings allow for this information to be set alongside other research in different contexts. The dependability of the research is enhanced by the involvement of the thesis supervisor in reviewing the analysis and the ability to follow-up with some individuals to ensure clarity of information.

Confirmability can only be invoked once credibility, transferability and dependability have been demonstrated. Confirmability requires critical reflexivity on the part of the researcher. Critical reflexivity is the researcher's own reflections and assumptions about the research questions (McLeod, 2001). Josselson (2007) points out that within qualitative research the role and contribution of the researcher as the primary data collector is crucial, because personal values, assumptions and biases may influence data collection and analysis. The researcher gave the women in the groups additional information about de-infibulation, antenatal care, childbirth and contraceptives so that they could participate in a more informed

way. By describing individual stories and experiences the researcher was able to reduce observation bias so that the women "spoke for themselves".

5.3 Summary of findings

Overall, the East African women with FGM, living in Christchurch, who were the subject of this research project reported health problems arising from FGM that are consistent with international experience. The women reported immediate health complications of FGM similar to those reported in the literature, including bleeding and the risk of haemorrhage, pain, infection and urine retention (El-Defrawi et al., 2001; Dare et al., 2004; Malmström, 2007) and in FGM type III (Boddy, 1989; Dirie and Lindmark, 1992; Chalmers and Hashi, 2000).

With regard to longer term complications, the East African women with FGM, who are living in Christchurch, commented on the negative effects of recurrent cutting and stitching (de-infibulation and re-infibulation). Infibulation has been reported in the literature as intensifying the negative aspects of recurrent cutting and stitching and formation of scars creating problems for delivery (Daw; 970). Pritchard (1969) describes, for example, prolonged second stage of labour due to vulval scarring in three Sudanese women in the UK with FGM type III. Among other severe consequences women reported specific problems related to fertility (such as PID and ectopic pregnancy) (Llewellyn-Jones et al., 1999), as well as adverse obstetric experiences such as early or late pregnancy bleeding and the risk of postpartum haemorrhage (Egwuatu and Agugua, 1981). As found elsewhere, such as Toubia (1998), psychological impacts of FGM and psychosomatic problems were also reported by these Christchurch women, and also consistent with overseas other research, these women will rarely spoke directly about a psychosocial problem, but presented with a physical complaint.

The thematic analysis reported in Chapter 4 identified four themes from the focus group interviews with women. The first theme that emerged was that the women acknowledged that they had received excellent clinical care and in childbirth had had healthy babies, but they also reported (theme 2) being extremely concerned about de-infibulation as part of their antenatal and maternity care. The *FGM Clinical Care: Antenatal, Labour and Birth and Postnatal Guidelines* (2009) for New Zealand indicate that there are two opportunities for de-infibulation: during antenatal care at approximately 24 weeks and during the second stage of labour. No women in the focus groups reported de-infibulation during the antenatal period. A number of participants in the focus groups reported episiotomy during labour. However, de-infibulation as part of antenatal care (or earlier) means that health professionals, who may be unfamiliar with the procedure, are not confronted with the need to perform de-infibulation during labour (McCaffrey et al., 1995).

Subsequent suturing of the incision does not involve restoring the scar site to a state of re-infibulation as this is illegal in New Zealand and contrary to the *Guidelines for De-infibulation* (2004). These Guidelines are intended for use in conjunction with *Female Genital Mutilation in New Zealand - A Guide for Health and Child Protection Professionals* (2004). These excellent clinical and social guides are available from www.fgm.co.nz, and can also be accessed via the Ministry of Health website. These were not mentioned by any of the providers interviewed, but providers clearly recognised their own need for more specific training and information.

The Christchurch Polytechnic Institute of Technology (CPIT) also ensures that midwives in training receive an orientation to the clinical and cultural issues of FGM. It is not clear whether other professional groups (for example, medical, Registered Nursing, social work) receive formal training, although occasional continuing education programmes may be available. Clearly, however, despite the care and empathy, encountered by the women in this

study, health professionals are likely to need additional training in the care and management of women who have FGM.

The question of access to surgical de-infibulation, outside pregnancy and childbirth has already been mentioned, and it is useful if de-infibulation is available, particularly to young women. The difficulties of infibulation for young women were highlighted in the interviews, including the question of access to surgical de-infibulation in New Zealand, not associated with childbirth. Women understood that there are services available to support young migrant girls with FGM in New Zealand to prevent PID, recurrent urinary infections, pain during menstruation and easing first sexual intercourse. Young girls or their parents can ask their GP for de-infibulation, and this is happening among more educated families.

The third and fourth themes, the barriers to knowledge among women about reproductive health and childbirth and the cultural and communication barriers are closely related. There are some written resources, but these are not always suitable for women with limited language skills. Women called attention to how their own limited knowledge of English and "health language" affected them greatly and caused them to feel very upset. Even when material is available in East African and Arabic languages, many women, because of their long stays in refugee camps, may not be literate even in their own languages. While the medical consequences of FGM have been generally well investigated, there has been much less research into the impact on the psychological health of FGM as a violation of a woman's physical intactness, and is a source of psychological trauma and a potential cause of post-traumatic stress disorder (PTSD).

There are some gaps for health providers. While midwives now appear to have a systematic orientation to FGM and women's needs, the situation is less certain for other groups such as doctors, Registered Nurses, interpreters, or social workers, and the extent of understanding

about the psycho-social issues surrounding FGM is not well known. The work of Garvey-Graham (2008) has already been noted as significant in this respect in New Zealand. This concern was expressed not only historically, as an absence of the topic in respect to the midwifery curriculum of the time, but also as a lack of contemporary educational opportunities as part of continuing professional development (Garvey-Graham 2008, page 47). Most encouraging has been the support of the primary care services for this research (Partnership Health-Pegasus Health PHO), which indicates that in Christchurch at least that there is a formal commitment to improving services for women with FGM and for their health service providers.

5.4 Implications for the future

Overall, there are limited suitable resources available to women with FGM. A special clinic, as in the Waitamata DHB, probably cannot be justified in Christchurch, given the relatively small numbers of women involved. However, primary care recognises the issues, and the support for this project from Partnership Health-Pegasus Health indicates concern for both this patient group and the need to support primary care professionals.

In one sense the knowledge gap is the heart of the problem. With knowledge, many of the identified problems would simply not occur, or would be at a very low level and more easily minimised. With suitable knowledge many of the cultural uncertainties for both women and providers would be absent, there would be a greater level of understanding and expectations that would be more clearly acknowledged and understood. With appropriate knowledge some of the perceived trauma of de-infibulation would be lessened and an understanding of the physiological potential of the de-infibulated state would help acceptance of action by both women and their communities, consistent with the law of New Zealand.

Many of the physical consequences of FGM can be repaired if they are well understood, detected and treated early. Early acknowledgement of FGM by health providers during maternity consultation is important to assist in awareness of the early warning psychosocial signs. Women need support, both with the provision of interpreters and counselling, not only during pregnancy but also, for example, during cervical screening and screening for sexually transmitted disease and HIV.

Four recommendations arise from this research:

- Additional health education and counselling support for women with FGM to build both knowledge and confidence
- Continuing professional development for specialist health providers involved in hospital and maternity care, particularly in an understanding of infibulation and de-infibulation
- Professional development for primary care professionals to ensure the establishment of strong relationships between the women's families and their general practice
- Continued research into the needs of women with FGM and other vulnerable groups to ensure effective health outcomes

Although the United Nations and many countries have outlawed FGM, there are conservative elements in some parts of the world that are still actively promoting the practice. Addressing the needs of East African women with FGM in Christchurch may seem remote from this, but it can be part of the wider effort to protect the health of the most vulnerable in the community and to ensure that this community awareness can support international efforts to stop the practice of female genital mutilation.

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Appendices

Appendix 1: Information and Consent form for women with FGM

Appendix 2: Interview Guide for focus groups of women with FGM

Appendix 3: Information and Consent form for health service providers

Appendix 4 Interview Guide for health service providers

Appendix 1: Information and Consent form for women with FGM

Health Sciences Centre
University of Canterbury
PB 4800
CHRISTCHURCH
20 June 2011



INFORMATION SHEET

Study title: Impact of Female Genital Mutilation (FGM) on the health women in Christchurch

I am a Masters student at the Health Sciences Centre at the University of Canterbury.

You are invited to take part in an important research study. The purpose of this research is to understand the situation of both in Christchurch women with FGM and their health providers, in order to increase knowledge of FGM and ensure improved health services with this condition.

Please take time to read the following information carefully and discuss it with others if you wish. Please contact us if you need more information, and take time (up to two weeks) to decide whether or not you wish to take part. If you take part you will be asked to sign a consent form confirming your agreement to participate.

We are asking you to participate in a group interview, at a time and place convenient to you, with other women who have experienced FGM. This will be taped and transcribed and will be conducted in a language that you understand, with interpreters present. We will supply refreshments at the event and provide either a petrol or grocery voucher worth \$30 in recognition of your time and expense in attending. We plan to discuss the impact of FGM on your health and the need for special health care for women in your situation.

Participation is voluntary, you can withdraw from the study at any time without giving a reason and if you decline to participate or withdraw at any time this will not affect you or your future care in any way. Your taking part in this study will be kept completely confidential.

All information which is collected about you during the course of the research will be kept confidential. No participant will be identified in any aspect of the report from this study or publication. Data, including audiotapes, will have no identifying information and will be stored in locked cabinet in the Health Sciences Centre, University of Canterbury. A summary of the results will be made available to you if you wish.

This research project is being carried out as part of the requirement for a Master's degree in Health Sciences from the University of Canterbury. Both the Health Sciences Centre and Partnership Health PHO are contributing funds towards the study.

If you have any further questions or concerns about the study or your participation in the study please feel free to contact me, Marian A. Hussen (mariana.deen@hotmail.com) or call me 033791953 NZAF, or mobile no 021866041. Or contact my supervisor Associate Professor Pauline Barnett (pauline.barnett@canterbury.ac.nz; tel 3667001 ext 3692)

Thank you for reading this.
Marian

Marian Hussen,
Graduate student

Canterbury Regional Health and Disability Ethics Committee (A): Approval number:

Health Sciences Centre
University of Canterbury
PB 4800
CHRISTCHURCH



20 June 2011

Consent to participate in research

Study title: Impact of Female Genital Mutilation (FGM) on the health women in Christchurch

Researcher: Marian Hussen

Instructions

Please read the information below and sign below to consent to participate in this study. Then please enclose this sheet in the self-addressed envelope supplied. Thank you.

If you wish to consent to participating in this study:

1. I have read the Information Sheet for this study, dated 20 June 2011, and I understand that I may ask further questions at anytime.
2. I understand that I am free to withdraw from the study at anytime, or to decline to answer any particular questions.
3. I agree to provide information to the researcher under the conditions of confidentiality set out on the Information Sheet.
4. I wish to participate in this study under the conditions set out in the Information Sheet.
5. I understand that if I have any queries or concerns at any stage I can contact Marian Hussen or her supervisor Associate Professor Pauline Barnett at the Health Sciences Centre, University of Canterbury.

Contact details: Marian A. Hussen (marianadeen@hotmail.com), or tel 033791953 (mobile) 021866041.
Associate Professor Pauline Barnett (pauline.barnett@canterbury.ac.nz; tel 3667001 ext 3692)

I understand that if I have any queries or concerns regarding my rights as a participant in this study, I may wish to contact an independent Health and Disability Advocate (New Zealand wide) as follows:

Free Phone: 0800 555 050
Free Fax: 0800 2787 7678 (0800 2SUPPORT)
Email: advocacy@hdc.org.nz
Website: advocacyhdc.org.nz

_____ Please tick if you wish to receive a summary of the study when completed

Name (please print): _____ Date: _____

Signature: _____

Canterbury Health and Disability Ethics Committee (A) Approval Number:

Appendix 2: Interview Guide for focus groups of women with FGM

Health Sciences Centre
University of Canterbury
PB 4800
CHRISTCHURCH



Impact of Female Genital Mutilation on the health women in Christchurch

Interview Guide – Topics to be covered in the focus groups for women who have undergone FGM.

Below are the broad topic areas to be covered through questions, discussion and follow up

- 1 Migration circumstances and length of time in Christchurch
- 2 Patterns of health service use
- 3 Health services that work well for women with FGM
- 4 Problems with health services for women with FGM
- 5 Impact of FGM on health
- 6 What can be done to improve services for women with FGM?

Appendix 3: Information and Consent form for health service providers

Health Sciences Centre
University of Canterbury
PB 4800
CHRISTCHURCH



20 June 2011

Consent to participate in research: health providers

Study title: Impact of Female Genital Mutilation (FGM) on the health women in Christchurch

Researcher: Marian Hussen

Instructions

Please read the information below and sign below to consent to participate in this study. Then please enclose this sheet in the self-addressed envelope supplied. Thank you.

If you wish to consent to participating in this study:

1. I have read the Information Sheet for this study, dated 20 June 2011, and I understand that I may ask further questions at any time.
2. I understand that I am free to withdraw from the study at any time, or to decline to answer any particular questions.
3. I agree to provide information to the researcher under the conditions of confidentiality set out on the Information Sheet.
4. I wish to participate in this study under the conditions set out in the Information Sheet.
5. I confirm that the information sheet and this form have been explained to me in my preferred language.
6. I understand that if I have any queries or concerns at any stage I can contact Marian Hussen or her supervisor Associate Professor Pauline Barnett at the Health Sciences Centre, University of Canterbury.

Contact details: Marian A. Hussen (marianadecn@hotmail.com), or tel 033791953 (mobile) 021866041.

Associate Professor Pauline Barnett (pauline.barnett@canterbury.ac.nz; tel 3667001 ext 3692)

I understand that if I have any queries or concerns regarding my rights as a participant in this study, I may wish to contact an independent Health and Disability Advocate (New Zealand wide) as follows:

Free Phone: 0800 555 050
Free Fax: 0800 2787 7678 (0800 2 SUPPORT)
Email: advocacy@hdc.org.nz
Website: advocacy.hdc.org.nz

_____ Please tick if you wish to receive a summary of the study when completed

Name (please print)

Date: 3.12.2013

Signature: _____

Project explained I

Date _____

Signature _____ *M. M. M.*

Upper South A Regional Ethics Committee Approval Number: UAR/11/07/034

Appendix 4: Interview Guide for health providers

Health Sciences Centre
University of Canterbury
PB 4800
CHRISTCHURCH



Impact of Female Genital Mutilation on the health women in Christchurch

Interview Guide for health service providers

- 1 Background to your involvement with FGM women
- 2 What are the main clinical problems that you encounter among this group of women?
- 3 To what extent have services improved over the last decade?
- 4 What are the main barriers to effective service provision?
- 5 What can be done to help improve health services for women with FGM?
- 6 Are there any other comments you wish to make?