

**Stories and strategies of women living with Female Genital Mutilation in  
Auckland communities**

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## Table of Contents

List of Figures .....	vi
List of Tables.....	vii
Attestation of Authorship.....	viii
<b>Acknowledgements</b> .....	ix
<b>Abstract</b> .....	x
Chapter 1: Introduction .....	1
1.1 Background to the thesis .....	1
<i>Origins of FGM</i> .....	3
<i>Prevalence and distribution of FGM</i> .....	3
<i>Health Impact of FGM</i> .....	4
1.2 Responses to FGM in New Zealand .....	6
<i>International response to FGM</i> .....	8
1.3 Theoretical Frameworks.....	9
1.4 Research question.....	11
1.5 Research positionality and background .....	12
1.6 Contribution to public health .....	13
1.7 Structure of the thesis.....	13
Chapter 2: Past to current issues in FGM: A literature review .....	15
2.1 Introduction .....	15
Inclusion criteria and Exclusion criteria .....	16

2.2 A historic look at FGM Literature .....	19
2.3 Themes in the current literature .....	19
<i>Theme One: Health Complications</i> .....	19
<i>Theme Two: Communication with health workers and their knowledge</i> .....	21
<i>Theme Three: Cultural importance</i> .....	22
2.4 FGM practicing communities in Auckland .....	23
Kurdish communities .....	25
Eritrean communities .....	26
Indonesian communities .....	27
2.5 Global / local response to FGM .....	27
<i>Global response to FGM</i> .....	27
<i>Local response to FGM</i> .....	29
2.6 Conclusion- A way forward for FGM .....	30
Chapter 3: Research Methodology and Methods .....	34
3.1 Introduction .....	34
3.2 Methodology .....	34
<i>Methods</i> .....	35
<i>Study location</i> .....	36
<i>Selection criteria and participant numbers</i> .....	36
<i>Characteristics of the participants</i> .....	37
<i>Recruitment process</i> .....	38
3.3 Data collection .....	39

3.4 Data Analysis .....	40
3.5 Ethical considerations .....	43
<i>Informed consent</i> .....	43
<i>Confidentiality and anonymity</i> .....	43
3.6 Conclusion .....	44
Chapter 4: Research findings from the study of Auckland women living with FGM ...	46
4.1 Introduction .....	46
4.2 <i>The practice of FGM and women’s FGM stories</i> .....	47
4.3 <i>Culture or Religions?</i> .....	50
4.4 <i>Health consequences</i> .....	54
4.5 Experiences of FGM in New Zealand.....	56
<i>Community attitudes towards FGM in NZ</i> .....	56
<i>Health care professional’s attitudes</i> .....	57
4.6 Suggestions for addressed and effectively preventing FGM among practicing communities in NZ.....	59
<i>Education</i> .....	59
<i>Laws and legislation</i> .....	60
4.7 Conclusion .....	61
Chapter 5: Discussion and Recommendations.....	62
5.1 Introduction .....	62
5.2 Summary of the findings.....	63
<i>The practice of FGM and women’s FGM stories</i> .....	63

<i>Culture or religions?</i> .....	64
<i>Health and psychosocial consequences</i> .....	65
<i>Experiences of FGM in New Zealand</i> .....	66
<i>Community attitudes towards FGM</i> .....	66
<i>Health care professional's attitudes</i> .....	66
<i>Suggestions for addressing and effectively preventing FGM among practicing communities in New Zealand</i> .....	67
<i>Education</i> .....	67
<i>Legislation</i> .....	67
5.3 The way forward: A Culturally-appropriate Human Rights approach to end FGM? .....	68
5.4 Implications for FGM prevention in New Zealand.....	70
<i>New Zealand FGM Education programme</i> .....	71
<i>Other Initiatives in New Zealand</i> .....	72
<i>Initiatives which relate to communities practicing FGM outside New Zealand</i> .....	72
5.5 Limitations and benefits of the research .....	73
5.6 Conclusion .....	73
References .....	75
Appendices .....	88
Appendix A: Poster advertising the research .....	89
Appendix B: Information Sheet .....	90
Appendix C: Consent Form .....	94
Appendix D: Ethics approval .....	96

## List of Figures

<i>Figure 1: FGM practice in African countries</i> .....	3
<i>Figure 2: Trends in FGM prevalence</i> .....	9
<i>Figure 3: Mode of the determinants of health</i> .....	10

## List of Tables

Table 1: Studies included along with the design, methods, number of participants in the study key findings and country that studies were conducted in.....	16
Table 2: Summarises the background information about the participate.....	37
Table 3: International by binding instruments applicable to FGM.....	69

## **Attestation of Authorship**

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

Signed: 

Ayan Mohamud Said

Dated: May 4 2015

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Ethics approval for the research has been obtained by the Auckland University of Technology Ethics Committee (AUTEK) on 4 August 2014: AUTEK approval number 14/105.

## **Abstract**

**Background:** Female Genital Mutilation (FGM) is a significant health problem for young girls and women; it is a harmful cultural practice that involves the cutting of the external genitalia. FGM has been practiced for thousands of years in a number of communities and there are efforts around the world aiming to prevent the continuation of this practice. However, given the longstanding and socio-cultural nature of FGM it is a difficult problem to address. As a result of international migration flows from practicing countries during the 1990s, FGM has become an issue of increasing concern in host countries such as New Zealand.

**Aim:** The aim of this study is to explore the stories of women living with FGM in Auckland, and to capture the strategies they propose for addressing FGM, with a focus on the Somali, Eritrean, Indonesian and Kurdish communities.

**Methods:** A qualitative descriptive methodology was undertaken using four semi-structured individual interviews and one focus group discussion (FGD) with one woman from each of the communities; Somali, Eritrean, Indonesian and Kurdish. The transcripts were analysed thematically.

**Findings:** Participants were most keen to share their personal stories through the research. Those who remembered the experience (2 women) spoke of the physical and emotional trauma of the event. All discussed long-term socio-cultural and health effects. One person gave details of their experiences with the New Zealand healthcare system. There was discussion about strategies and they mainly consider education as central to prevention; also the law is seen as a deterrent to FGM practice but they had little knowledge of the rights' debates.

**Conclusion:** Despite decades of prevention programmes and global rights based legislation and targets there has been little shift in FGM prevalence internationally. This

thesis argues that there is a need for strategies to prevent FGM that use a more culturally appropriate and community based approach, moving beyond global statements. These strategies also apply to the New Zealand context, which needs to take into consideration the diversity of FGM practicing communities.

Keywords: Female genital mutilation (FGM), Somali, Eritrean, Indonesian, Kurdish, New Zealand.

## **Chapter 1: Introduction**

### **1.1 Background to the thesis**

The World Health Organization [WHO] defines Female Genital Mutilation (FGM) as all procedures involving the removal of the external female genitalia for any reason whether it is for cultural reasons or a non-therapeutic reason (2008). Literature suggests that FGM is a complex and multifaceted practice which is deeply rooted in cultural, social and religious belief (Abdulcadir, Margairaz, Boulvain, & Irion, 2011; Denholm, 2004; World Health Organization [WHO], 2008). This ancient traditional practice which has existed for 2000 years can only be understood in the social cultural context in which it is practiced (Abdulcadir, Margairaz, Boulvain, & Irion, 2011; WHO, 2008 ; WHO, 2001). FGM is associated with many negative physical and psychological health consequences for women (Abdulcadir, Margairaz, Boulvain, & Irion, 2011).

WHO (2008) groups FGM into four types. In communities where FGM is practiced Type I and Type II are often referred to as Sunna-circumcision which means tradition. In Arabic Type I which is known as clitoridectomy the excision of the clitoris takes place. This is where part or the entire clitoris is removed (UNICEF, 2010; WHO, 2008). Type II is also known as excision is the removal of the clitoris and also part or all of the labia minora. Type III infibulation is the total removal of the external genitalia which is then followed up with the stitching/narrowing of the vaginal opening (UNICEF, 2010; WHO, 2008). Type IV is unclassified; this includes everything such as the pricking, piercing, burning of the clitoris and/or labia and introduction of corrosive substances or herbs into the vagina for the purposes of tightening or narrowing the vagina. Type I and Type II are most common forms of FGM with around 80 per cent of

all women and young girls whom have been subjected to FGM have had Type I or Type II carried out on them (WHO, 2010). Type III which is considered the most extreme type of FGM is the least common type of FGM worldwide; about 10 per cent of women being subject to type this type (Bagness, 2015; WHO, 2010).

The terminology applied to the practices of FGM has undergone various changes. There are a number of different terms used to refer to the practice of Female genital mutilation, the most common ones being female circumcision (FC) and female genital cutting (FGC) (WHO, 2008). Initially the practise of FGM was referred to as FC however the use of the term FC is discouraged in a clinical setting, as it is anatomically incorrect and provides a misleading parallel with male circumcision, As a result, creates confusion between these two distinct practices (UNICEF, 2010)

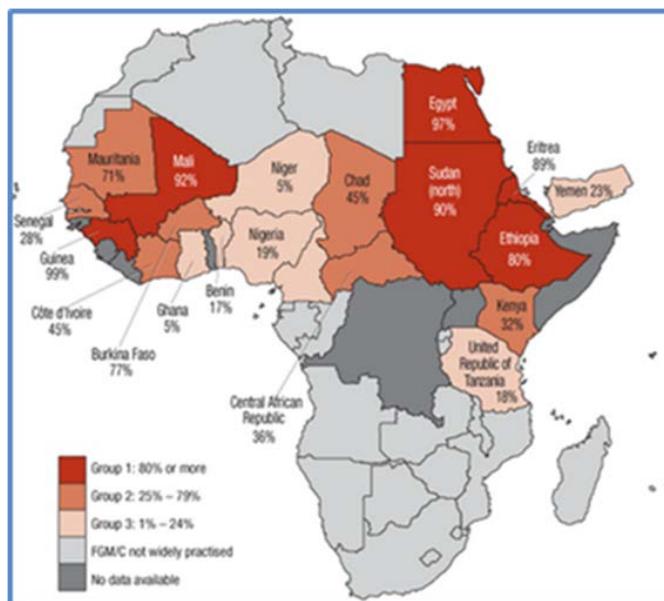
Internationally, the term 'female genital mutilation' is used to highlight the physical, emotional, and psychological consequences associated with the practice FGM is widely seen as a harmful practice and is recognised as a violation of human rights of young girls and women and the use of the word mutilation emphasises that this practice is a violation of human rights (Population Reference Bureau, 2008). Another term that is often used to describe FGM is female genital cutting. This is another term that is used by health advocates and health programmes that are designed to bring a stop to FGM (Population Reference Bureau, 2008). FGM is an appropriate term for medical use and the recommended term for use at policy level as defined by WHO (UNICEF, 2010). When working with communities affected by FGM however, the term female genital mutilation may cause offence and should generally be avoided. When referring to FGM, it is more appropriate to use terms that women and their families are familiar with; female genital cutting is used as a non-judgmental term (The FGM Education Programme, 2011).

## *Origins of FGM*

Beliefs surrounding the origins of FGM vary greatly. It is often believed to have originated in ancient Egypt and had spread from there to other parts of Africa. During the pre-Islamic era it was common practice in Egypt, Arabia, and along the coast of the Red Sea. The first record of the practices of FGM was made by a Greek geographer and a historian named Strabo who reported excision which is Type II FGM on young Egyptian girl around 25BC (Denholm , 2004;Johnsdotter, & Essen,2005). Back then the term 'pharaonic circumcision' was used for the FGM practices (Ogunsiji, Wilkes, & Jackson, 2007). Generally FGM is seen as a rite of passage for girls to enter womanhood. The age at which FGM is carried out varies from country to country and it is most commonly carried out between the ages of four and thirteen. Some communities however, practice FGM before the age of one and at times can be carried out on woman just before they get married (Denholm, 2004).

## *Prevalence and distribution of FGM*

*Figure 1: FGM practice in African countries*



Sources: (World Health Organization, 2008).

Figure 1 shows that FGM is practiced and presents within 28 African nations mainly located in sub Saharan Africa, parts of the Middle East and in some parts of Asia (Wheeler, 2003; Denholm, 2004; WHO, 2008; World Health Organisation, 2010). Due to the fact that more people migrate around the world; FGM gaining attention in countries where the communities that practice have migrated to; such as Australia, Canada, New Zealand and the US (Boyle, Songora & Foss, 2001; Momoh, 2014). As noted earlier, the prevalence of FGM varies between countries and within different ethnic groups (The FGM Education Programme, 2011). The highest prevalence of FGM has been found in Somalia, which is as high as 97.9 per cent; while in Uganda, the prevalence is as low as low as 0.6 per cent (Denholm, 2004). FGM is a practice that is practiced among different religions such as Islam, Christianity and in Judaism (World Health Organization, 2001; Jaeger, Caflisch, & Hohlfeld, 2009).

#### *Health Impact of FGM*

FGM is a harmful cultural practice that has many side effects; there are both physical and psychological health outcomes from undergoing FGM. FGM is often carried out by traditional practitioners without the use of anaesthesia, using unsterile cutting devices such as knives, razors, scissors, cut glass, or sharpened rocks (Berg, & Denison, 2013). The health complications that young girls and women endure depend on the different types of FGM. There are a range of short-term as well as long term consequences that are associated with FGM and the most commonly reported complications are things like that of shock which results from bleeding, pain and stress due to cutting very sensitive and delicate areas of the genitalia without the use of anaesthetic (O'Connell, 2014; Momoh, 2014; Ogunsiyi, 2015). Haemorrhage can occur after FGM, the cutting of the blood vessels in the clitoral artery during the procedure can lead to bleeding. If serious bleeding occurs this could be due to shock. Protracted

bleeding can lead to anaemia or even death (Andro, Cambois, & Lesclingand, 2014; Denholm, 2004).

Other short term health consequences that are caused by FGM include urinary retraction which is a common health outcome because often young girls have a fear of urinating on newly damaged tissue which causes pain and in some cases this may cause death (Jaeger, Caflisch, & Hohlfield, 2009). Also tissue swelling or injury of the urethra may cause pain and discomfort which could easily lead to bladder and urinary tract infections. Infection caused by the use of unsterilized instruments within an unhygienic environment may result in other complications and even death. Infections can also cause pelvic inflammation. It could result directly in blood poisoning and in having tetanus, and if untreated death may eventually follow. There is also a high risk of HIV transmission through the use of one instrument for multiple operations. Damage to organs such as the anus, urethra and the bladder from inexperienced circumcisers often occurs ((Reisel, & Creighton, 2015)

Long-term physical health complications that may arise as a result of FGM can include things such as fistulae and recurrent urinary tract infection (Andro, Cambois, & Lesclingand, 2014). HIV transmission is an issue where group circumcision happens as a circumciser goes from one girl to another. In this process the tools used for circumcision are often not cleaned and are therefore not sterile resulting in long-term complications. Difficulties with sexual health screening as well as complications during labour are just some of the long term physical health complications (Andro, Cambois, & Lesclingand, 2014). The psychological health complications that are commonly seen in females that have gone through FGM are things like fear, loss of trust, anxiety and depression (Denholm, 2004; Mulongo, Hollins Martin, & McAndrew, 2014; Utz-Billing, & Kentenich, 2008).

## **1.2 Responses to FGM in New Zealand**

The practice of FGM is serious a global public health issue. On a global scale, there are around three million girls at risk of undergoing FGM every year (WHO, 2008). FGM as a global health issues was recognised by the World Health Organization only about 20 years ago or in early 1990s. FGM on a global level is also viewed as a violation of human rights (Easton, Monkman &Mils, 2003). There was an increased number of refugee women settling in New Zealand in early 90's who came from countries where FGM is practiced; especially those who came from Africa (Mortensen, 2011; Perumal, 2010). In New Zealand the communities which have been mostly affected by FGM are from Somalia, Eritrea, Ethiopia and Sudan. International literature also suggests that the practice of FGM is also being carried out among the Muslim community in India, Malaysia and Indonesia. Girls and women from these communities now live in New Zealand and have undergone the practice of FGM prior to their arrival in New Zealand (The FGM Education Programme, 2011).

Every year New Zealand grants refugee status to 750 refugees (Mortensen, 2011). In New Zealand there are no public health policies that directly address the issues of FGM but programmes related to FGM are in the New Zealand Health Strategy (2000) which it provides a framework for health sectors to improve the overall health and well-being of all New Zealanders. This guideline addresses the need to work with ethnic minorities and those who are marginalised to promote health equalities, especially focusing on improving the health status of Maori, Pacific communities or people of low socio-economic background and refugees who have settled in New

Zealand. Refugees who settle in New Zealand are often from countries of conflict, which means they come to New Zealand bringing nothing hence are in a lower economic bracket. Within the New Zealand Health Strategy, efforts to reduce health inequalities include better access and appropriate services addressing the needs of people from a lower socioeconomic group (Ministry of Health, 2000).

FGM is illegal in New Zealand for the reason that the practice is seen to be harmful and that this practice is considered to be violating human rights. FGM is illegal under an amendment to the Crimes Act 1961, section 204A. Any procedure that is for reasons related to culture and religion which involves the mutilation of the vagina or clitoris is illegal (Perumal, 2010). New Zealand is a signatory of a number of international instruments and conventions that call for an end to FGM; such as the Universal Declaration of Human Rights and The Convention on the Rights of the Child (CRC) (The FGM Education Programme, 2011). Other western countries that have put into place law that stop the practices of FGM include UK, France, Canada and the United States of America. Some states in Australia also have law on FGM (Unicef, 2010).

In 1997 responding to the rising number of women and girls from countries that practice FGM and settled in New Zealand in 1997, a community based FGM Education Programme was set up in 1997 (The FGM Education Programme, 2011). So far this is the only programme available to improve reproductive health care services for women and girls who are affected by FGM. This programme offers training and support, and to prevent the occurrence of FGM in New Zealand through community education and health promotion. This programme is funded by the New Zealand Ministry of Health (The FGM Education Programme, 2011). The FGM New Zealand programme also develops education resources for communities, health and child protection workers;

provide information, training and support for health professionals (ie midwifery, medical and nursing students. Unfortunately, this programme is only funded for Auckland region. Therefore trainings and support for health professionals are not available for professionals, medical students or nurses and midwives from outside Auckland (The FGM Education Programme, 2011).

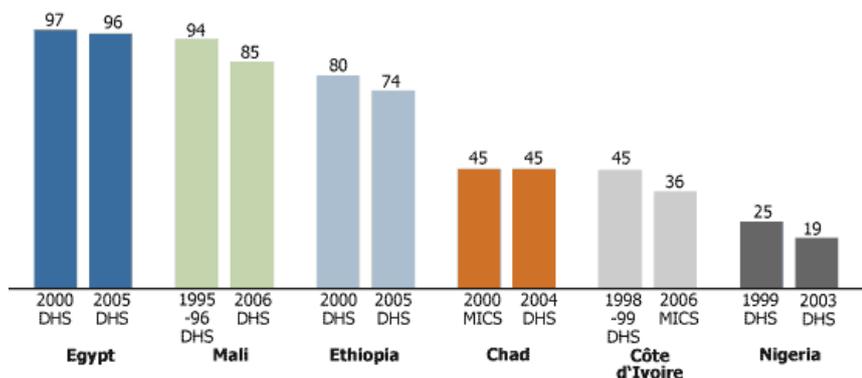
### *International response to FGM*

There have been many global efforts made to end the practice of FGM such as the WHO, UNICEF and UNFPA released a joint statement calling for the abandonment of FGM. They have also funded research and developed resources and international guidelines for policy makers and health care professionals in dealing with women and girls who are affected by FGM. By developing these international guidelines there is a set standard for the governments and health care provider to operate from (World Bank, 2004). The United Nations has made that 8th of February the international Day of Zero Tolerance of Female Genital Mutilation. To bring an end to FGM there needs to be a strong political commitment to bring about change. As of 2009 there was a total of 20 African countries that have implemented legislation against the practice of FGM. Thirteen industrialised countries that receive immigrants from countries where FGM is practised have also implemented specific legislation criminalising the practise. In countries such as the United States and Australia only some of the states have legislation in place.

Over the last 30 to 40 years there have been many efforts made to eliminate FGM through a range of community, regional, national and international programmes (Bulletin of the WHO, 2014). Many of the successful programmes have applied a social change approach through a process of community dialogue and partnerships between the community, non-government agencies and government. The past three

decades have shown that there is no quick and easy solution to eliminating FGM. Figure 2 shows that through a range of activities there is a downward trend in the per cent of women being subject to FGM over ten year period. In some countries there is little or no change at all which highlights that there is still more to be done. Given the differences between communities and the differing contexts in which FGM occurs each country must develop its own specific strategies that are workable at the local level (Population Reference Bureau, 2010).

*Figure 2: Trends in FGM prevalence*



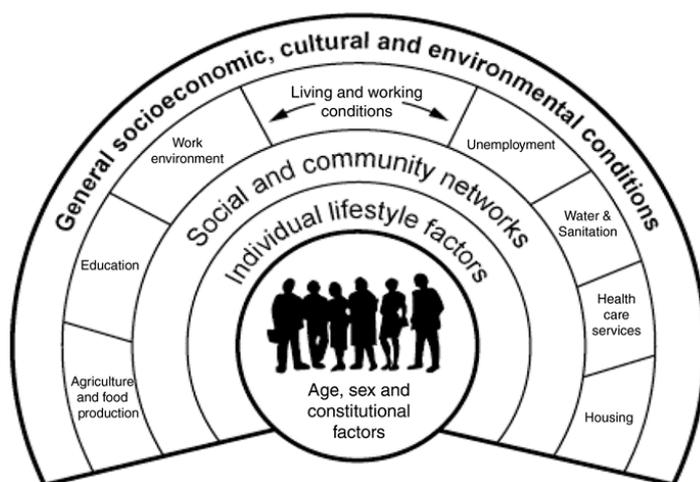
Sources: (Population Reference Bureau, 2010).

### 1.3 Theoretical Frameworks

Health is known to be linked to the biological, background, behavioural choices and the psychological status of the individual health (Baum, 2008). The health status of a population is not distributed equally and varies within a country and around the world (Baum, 2008). There are a ranges of factors that have an impact on the health of an individual and the community such as social, cultural and economic factors. Health is shaped by the social conditions in which people are born in, grow in, live and work in. The health of people is influenced by many factors within and outside of the individual's control (Baum, 2008). Although each of the determinants of health are

important in contribute to the health status of individuals and communities, throughout life there is a complex interaction between different determinants of health (Navarro, 2008).

*Figure 3: Mode of the determinants of health*



Sources: (Dahlgren & Whitehead, 1991)

Dahlgren and Whitehead (1991) makes clear the constraints on individuals arising from social, cultural, economic and environmental factors .The determinants do not occur in isolation but interact with each other and together they influence the health status of individuals and populations. The practice of FGM is influenced by the determents of health such as social influences, community pressures and cultural influence. (Berg,& Denison,2013). The quote below is from a Somali midwife who understands the health impact of FGM; she says “I cannot sacrifice my child. Either way, she suffers. What am I to do? As a midwife I know the terrible health results. As a mother, I know how the child suffers from being teased, insulted and excluded by her friends. She will face even worse problems later when the family of the man to whom she will be given in marriage will turn her down as 'unfit'. How can we stop these operations as long as we know that if our girls are not circumcised - they will not find

husbands and they will blame their mother. Their lives will be ruined either way"(Denholm, 2004 p.89).

#### **1.4 Research question**

The aim of this study is to explore the stories of women living with FGM in Auckland, and to capture the strategies they propose for addressing FGM, with a focus on the Somali, Eritrean, Indonesian and Kurdish communities.

This research use a set of semi-structured questions to guide the individual interviews and also the focus group discussion (FGD);

1. From your experiences of listening to the stories of women who live with FGM in Auckland what themes and issues emerge?
  
2. How can FGM be addressed and effectively prevented among practising communities?
  
3. What barriers are there to preventing FGM?
  
4. What opportunities might assist in preventing FGM? (eg, useful sources of information)

Objects of this study

- To explore the literature on FGM.
  
- To explore the stories of women living with FGM in Auckland, and to capture the strategies they propose for addressing FGM.
  
- To make recommendations for FGM in the Auckland contexts.

A qualitative approach was chosen as the most appropriate research method to investigate the issues around FGM and due to the fact that FGM is a cultural tradition of which is practised by various cultures. The qualitative approach explores attitudes and social practices in order to understand the factors which influence decision-making in relation to FGM. In this study the method of data collection that is utilized is audio-recorded interviews and focus group discussion. Auckland University of Technology Ethics Committee (AUTEK) granted ethical approval for this research on August 5<sup>th</sup>, 2014.

### **1.5 Research positionality and background**

Research is influenced according to a particular worldview, or lens of the researcher (Gorman,& Clayton, 2005). This study is very much influenced and shaped by my upbringing, personal experiences and cultural background. My personal interest in the area of public health started when I was 18 years old when I heard about the issues of FGM. I was introduced to the topic as at this time my mother was working on a research project in New Zealand called Female Genital Mutilation; 2008 Health Care Survey Report (Denholm, & Powell, 2009). As a result my interest grew and I have been working with the FGM education programme over the last seven years. I have worked in youth and service provider and with child protection agencies. I was born in Somalia, 'back home' Somalia has one of the highest prevalence's of FGM in the world. As I was reading the research that had been done on FGM in New Zealand I realised that there is research conducted by a member of the affected community. These thoughts and experiences developed my interest in contributing to making a difference for women who are affected by FGM.

## **1.6 Contribution to public health**

The practice of female genital mutilation (FGM) has been practiced for thousands of years. WHO has recognised FGM as a health problem due to the number of young girls who are at risk of FGM each year. Every year on a global scale it is estimated that there are around 3 million girls at risk of undergoing these horrific procedures. WHO estimated that throughout the world there are between 100 and 140 million women and girls who have undergone such procedures (WHO, 2010). Public health is a field of health that is concerned primarily with improving the health of populations rather than just the health of individuals (Baum, 2008). Public health practitioners have an important role in the prevention of FGM as they are in a position where they can provide information and advocacy regarding FGM as well as supporting and informing patients and communities about the benefits of eliminating it altogether (WHO, 2008). This can be done by providing women with information about their own sexual and reproductive health, making it easier for them to understand natural body functions and the harmful consequences of FGM. Health care providers can also play an important role in community outreach, such as conducting school programs and public health education seminars (WHO, 2008).

## **1.7 Structure of the thesis**

The overall structure of the study takes the form of five chapters, chapter one is the introduction to the thesis it set the scene for the thesis it provides an overview of the research, highlighting why FGM is an issue for public health and outlining the research question. Chapter two contains literature published by different scholars, and organisations working on the issues of FGM; Chapter three presents the research

methods and methodology; Chapters four, contain the research findings and Chapter five presents the recommendations of the study and the conclusion.

## **Chapter 2: Past to current issues in FGM: A literature review**

*“It is a deep rooted custom in our culture, and people think it is an important operation for women because it prevents them from being oversexed. Uncircumcised girls are not accepted among our society. As you know, infibulation is a pre-requisite for marriage because no man wants to have an oversexed woman who becomes unfaithful after marriage. No family wants their daughter to have loose ways and bring shame to the family. Because of this, mothers make sure their daughters are properly circumcised and infibulated.”(Denholm, 2004 p23).*

### **2.1 Introduction**

Female genital mutilation (FGM) is a traditional cultural practice that affects many young girls and women. Over the years FGM has been a highly controversial and a complex topic. There has been much outrage expressed globally through the international media, with calls to bring FGM to an end (UNICEF, 2013). For the communities that practice FGM however, it holds a lot of cultural meaning (Ali, 2010). The aim of this chapter is to examine the published literature on the subject of FGM to find out what is known about the subject.

A literature search was conducted using the Auckland University of Technology's library databases. In the literature review the databases that were utilized are as follows: EBSCO Health Databases, MEDLINE via EBSCO, Google Scholar and Scopus with full texts. Peer-reviewed journal articles were identified that had relevance to the topic of FGM. The search for literature involved the use of the following keywords: female circumcision, female genital cutting, and female genital mutilation. I

also added female genital mutilation in Somali women, female genital mutilation in Eritrean communities, female genital mutilation in Kurdish communities, and female genital mutilation in Indonesian communities as additional terms.

### *Inclusion criteria and Exclusion criteria*

The inclusion criteria for this literature review relating to the subject of this thesis are a) that all articles are in the English language, b) all articles must be full text peer-reviewed research; c) on the topic of female genital mutilation (FGM); d) published between 2005 and 2014; e) and that the research was conducted in developed countries. In this literature review the exclusion criteria are that of articles published before 2005; not in English articles; not related to FGM or about surgical repair of FGM. Unpublished work and grey literature will also be excluded. There was a surprisingly small number of articles, 8 articles in total which meet the inclusion criteria. These are set out below.

*Table 1: Studies included along with the design, methods, number of participants in the study key findings and country that studies were conducted in.*

Title	Objectives	Design	Method	Results	Country
Berggren, Bergstrom, & Edberg (2006).	To explore the encounters with health care system in Sweden of women from Somalia, Eritrea and Sudan who have been genitally cut	Qualitative study	Interview 22 women	The results in this study indicate a need for more individualized culturally adjusted care and support and need for systematic education about female genital cutting for Swedish health care workers	Sweden
Gele, Kumar, Hjelde, & Sundby (2012).	To explore attitudes toward female circumcision among	Qualitative study	Interview 38 participants	This study found that Somalis in Oslo to a large extent changed their attitude	Oslo Norway

	Somali immigrants in Oslo		both male and female	toward the practice a large number of parents have left their daughters uncut .	
Johnsdotter, S. (2009).	To explore attitudes toward female genital cutting among Ethiopian and Eritrean in Sweden	Qualitative study	Thirty – three taped semi structured interview with both men and women	This study found firm rejection of all forms of FGM this study also find that Ethiopian and Eritrean parents living in Sweden run little risk of subjecting their daughters to FGC	Sweden
Khaja, K., Barkdull, C., Augustine, M., & Cunningham, D. (2009).	The study sets out to better understand the women’s experiences with and vies of FGM	Qualitative study	In-depth interviews with 17 women in both Canada and the USA	This study explored the law with respect to the law in both Canada and the USA the study explored the health complications	Canada and USA
Lundberg, P., & Gereziher, A. (2008).	To explore Eritrean immigrant women’s experiences of female genital mutilation during pregnancy childbirth and the postpartum period	Qualitative study using an ethnographic approach	Interview with 15 Eritrean women in their homes	The women had experiences of FGM had complications during pregnancy ,childbirth and postpartum period  Health care provider not have much knowledge about the cultural in order to be able to provide quality care to these women their need to be an increased understanding on the cultural	Sweden

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				It is important to inform the women about the Swedish law	
Straus, L., McEwen, A., & Hussein, F. (2009).	To examine cultural and social aspects of childbirth, and to determine how they intersect with the needs and experiences of Somali women in the UK	Qualitative study	In depth narrative interviews	Mismanagement of care of female circumcision provided during pregnancy and labour leads to problems for many Somalia women. Communication barriers with health care professional	UK
Thierfelder, C., Tanner, M., & Bodiang, C. (2005).	To explore the experience gynaecological/obstetrical care in swiss health care system	Qualitative study	Focus group discussion 29 women from Somalia and Eritrea and 37 telephone health care professionals	Swiss health care system does not deal with the specific needs of women with FGM counselling of the women is often inadequate lack of communication	Switzerland
Upvall, M., Mohammed, K., & Dodge, P. (2009).	To explore the perspectives on health of Somali refugees in relation to their condition as circumcised women	Qualitative study	Focus group and interview with a doctor Somali	FGM is considered a normal part of everyday life lack of knowledge among health care professional	USA

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I reviewed these 8 articles and identified the major themes which are discussed below in 2.3.

## **2.2 A historic look at FGM Literature**

FGM has been written about since the mid 1970's when the first academic paper was published focusing on FGM in Sudan. "The Hosken Report: Genital and Sexual Mutilation of Females" was the first research that showed a global perspective on the issues of FGM (Hosken, 1979). This report also gave the first global estimate of the scale of FGM with an estimated overall 110,529,000 women experiencing FGM (Hosken, 1979). The Hosken Report looked at 20 African countries and wrote about the different types of FGM and cultural reactions for the practice. I believe that the Hosken Report adopted a western mind set seeing FGM as a training ground for male violence. This report has been offensive to community use. However, it has been influential in informing the debates Fran Hosken shaped the way in which researchers explore the issues of FGM and also has influenced policy and practice in communities Hosken, 1981; Hosken, 1998).

## **2.3 Themes in the current literature**

### *Theme One: Health Complications*

Young girls suffer from FGM as children also at the time of their marriage as adults; and later during their child delivery. Female genital mutilation has detrimental effects on the physical and psychological health of the young girls and women who have been subject to undergo this practice (Thierfelder, Tanner, & Bodiang, 2005). The short-term consequences can begin immediately after the circumcision and up to occur ten days after (Lundberg, & Gereziher, 2008). The damage to and removal of healthy and normal female genital tissue interferes with the natural functions of girls' and women's bodies. Further, it is often carried out in unhygienic conditions without anaesthesia. Immediate complications can include severe pain and shock. Participants in the Upvall, Mohammed, & Dodge, 2009 study recalled their fear and pain during the procedure.

Long-term complications are life-long and often require medical attention to mitigate the effects. One study, for example, found that in the case of women who had been infibulated (Type 3 FGM) that there was long-term complications such as dysmenorrhoea, due to the mechanical obstacle to menstrual flow, inflammatory and/or psychosomatic factors. Other long-term complications are chronic pelvic infections; chronic or repeated vaginitis, especially after the first sexual intercourses (Thierfelder, Tanner, & Bodiang, 2005). Childbirth-related complications are also noted in the literature. Haemorrhage and infection can result in severe damage and may even seal the vaginal entrance during childbirth. The vaginal flesh may tear, obstructing labour putting both mother and child at grave risk (Lundberg, & Gerezgiher, 2008).

De-infibulation is the surgical procedure that reverses infibulation (Type 3, FGM). This is done by opening up the closed genital scar tissue (Lundberg & Gerezgiher, 2006). Participants in the studies expressed mixed views on de-infibulation as some of the women in their home country get re-infibulated for reasons of acceptability to them and their husbands. Participants in the studies also expressed experiences of extreme pain from de-infibulation; from having skin they did not have before rubbing against their underwear (Berggren, Bergstrom, & Edberg, 2006). Some participants wanted to be de-infibulated, but some health care workers refused. This made women believe that the health workers did not have the knowledge to perform de-infibulation (Berggren, Bergstrom, & Edberg, 2006 ; Lundberg & Gerezgiher, 2006). Other women had been de-infibulated by their husbands or birth attendants in their home country using knives or razor blades (Berggren, Bergstrom, & Edberg, 2006) (Lundberg & Gerezgiher, 2006).

Fear and anxiety is something that women who have been subject to FGM go through during different stages of their life. In two studies women talk about fear and anxiety both from the experiences during the procedure and also during pregnancy and

childbirth (Berggren, Bergstrom, & Edberg, 2006; Lundberg, & Gereziher, 2008).

During the experiences of being subject to the procedure of FGM the participants in the first study referred to themselves as victims as they were children who did not really understand what was happening. The women in the study talked about having flashbacks on the day they were circumcised. They spoke negatively about the practice using words like the most horrible and the most terrible experiences they have undergone when they remember what happened to them (Lundberg & Gereziher, 2008). As a lot of the women in the study were very young when circumcised there is a lot of fear around trusting people. This is because during circumcision, they were held down by force by the people closest to them such as their mother. Yet this is meant to be the person that should protect you when you are young (Berggren, Bergstrom, & Edberg, 2006; Lundberg & Gereziher, 2008). Some women feel as if their mothers betrayed them as they did not explain to them what was going to happen. Women experience flashbacks during pregnancy, childbirth and gynaecological examinations. As not a lot of people talk about FGM, women are often not informed about pregnancy and childbirth therefore making them worried and anxious about what would happen to them and their babies (Berggren, Bergstrom, & Edberg, 2006; Lundberg & Gereziher, 2008).

#### *Theme Two: Communication with health workers and their knowledge*

Participants in the studies experienced both positive and negative communication when it comes to dealing with health workers. The positive experiences related to the showing of kindness to women when they came to the hospital, and being available when women go back home. Sometimes women waited all day to see the doctor and still were sent home unseen. A lot of the participants talked about non-verbal communication as being negative. One participant recalled that at the hospital her health worker “looked at me there with faces full of disgust” (Berggren, Bergstrom, & Edberg,

2006 p.4). According to Berggren, Bergstrom, & Edberg, (2006) some of the participants in their study talked about having a health worker standing and talking about a woman without speaking to her. The women felt shame and described a fear of being not accepted, and women felt embarrassed (Berggren, Bergstrom, & Edberg, 2006) Participants also discussed how health workers did not ask them about FGM yet they did not want to bring it up themselves. This was a negative experience for the participants as back home every health worker knows about FGM.

A major theme is that health workers in developed countries lack knowledge. Positive experiences related to health worker knowledge of FGM or having worked in a country where FGM is common (Khaja, Barkdull, Augustine & Cunningham, 2009). The participants also highlighted that the more they understood about the health care system and how it worked the better their experiences were with health workers. Having a female interpreter was a positive factor in good health care (Lundberg & Gerezgiher, 2006). Women expressed a need for health workers from their own culture to hold health education meetings (Gele, Kumar, Hjelde, & Sundby, 2012). Participants expressed negative health care experiences. They talked about feeling rushed and having different health worker whereas in their home they would have one health worker (Berggren, Bergstrom, & Edberg, 2006).

### *Theme Three: Cultural importance*

Culture can be seen as a collection of learned beliefs, traditions and a code of common behaviour that is shared by members of a particular community (Polatajko et al ,2007). Many communities consider FGM as a traditional custom and as a part of their culture identity (Gele, Kumar, Hjelde, & Sundby, 2012). FGM is associated with cultural ideals of femininity, chastity and modesty and is thought to reduce a woman's libido. Girls are considered as clean and beautiful (Johnsdotter, 2009). Young girls and

women who have undergone FGM feel social acceptance and love, whereas coming to a western culture this transformed to negative meanings. They understood that FGM was a negative word and others thought they were victims of family violence and barbarity. Women expressed that they would like health workers to have an understanding that FGM is a very common part of their culture (Berggren, Bergstrom, & Edberg, 2006). Lundberg & Gerezgiher, (2006) state that women in this study talked about their home country as providing support and networks. The women talked about how they were taken care of for forty days and forty nights after giving birth by in their family and friends in the community (Berggren, Bergstrom, & Edberg, 2006).

#### **2.4 FGM practicing communities in Auckland**

There are a number of communities practicing FGM in Auckland. Here literature on four of the communities is discussed these that are the subject of the thesis. Somalia is one of the most homogeneous populations in Africa thus the common term Somalis. The most common and official language which is spoken in Somalia is Somali and it is understood by most Somalis (New Zealand Ministry of Health, 2012). Clan groups and memberships are central to Somali identity and tend to be associated with particular geographical areas in the horn of Africa (New Zealand Ministry of Health, 2012). In the time of the colonial era Somalia was divided into Italian, British and French colonial territories (World Bank, 2004). In the early 1960's Somalia became an independent state and stayed that way until the early 1990's when the government was overthrown and Somalia subsequently had gone into a civil war (Transitional Federal Government Mogadishu Somalia, 2010; Edna Adan University Hospital n.d). As a result of this latest war millions of Somali people fled to refugee camps in border countries such as Kenya, Ethiopia and Sudan (United Nations High Commissioner for Refugees, 2012).

Since the early 1990s, refugees from Somalia make up one of the largest groups of refugees in the world. Somalis have been coming to New Zealand as refugees since 1993 and are the second largest group coming into New Zealand after Afghans. The total population of Somalia refugees in New Zealand is estimated at around 2,800 and they have resettled in four main areas Auckland, Hamilton, Wellington and Christchurch (New Zealand Ministry of Health, 2012). On their arrival in New Zealand, the refugee group has poor health and this is a reflection of the circumstances from which they have come (Perumal, 2010). For example, prior to their arrival to New Zealand, refugees might have poor had living condition, experiencing trauma and fear and they had lived in refugee camps with little or no access to health care services (Mortensen, 2011). A large proportion of the refugees arriving in new host countries often have physical injuries, scarring and disability as a result of the traumatic experience with which they have been through such as war injury, landmines or major trauma they experience in a war zone (Morris, Popper, Rodwell, Brodine, & Brouwer, 2009; Bhui, Craig, Mohamud, Warfa, Stansfeld, Thornicroft, & McCrone, 2006). Somali refugees come from areas with little or no disease control, diagnosis, and treatment with no access to health care systems due to the civil war (Cote, Geltman, Nunn, Lituri, Henshaw & Garcia, 2004). On arrival they may have physical disability, severe dental problems and disease that they have picked up from being in a refugee camps or through the journey to which they got to the camps as there is limited access to clean water and nutritious food (Te Pou o Te Whakaaro Nui, 2010).

FGM has been practiced in Somalia for hundreds of years. The origins of this practice however are not well understood. This lack of understanding could be due to the fact that the Somali language was not a written language till the 1970's (World Bank, 2004). Among Somali girls and women 80 to 90 per cent have undergone Type III circumcision which is the complete removal of the external female genital and it

requires suturing of the tissues. This is the extreme type of female circumcision which often causes severe reproductive and sexual health problems (World Health Organisation, 2008). No differences in the type of circumcision were found across different socio and economic groups and urban versus rural areas in Somalia (World Bank, 2004).

### *Kurdish communities*

Iraqi Kurdistan, is located in the north-eastern part of Iraq, the population Iraqi Kurdistan over 4 million people who are a Kurdish ethnicity. Islam is the main religion there are also Christians and other ethnic and religious minorities inhabit the region, Arabs, Turkmen, and Yazidis (Saleem, Othman, Fattah, Hazim, & Adnan, 2013). In 1992 Iraqi Kurdistan become a self-ruled region. There were two larger waves of Iraq national coming to New Zealand in the 1990 when the Gulf war and in 2003, after an invasion led by American and British forces, they come to New Zealand as refugees (New Zealand Ministry of Health, 2012).

The issues of FGM has become a concern especially by women's organizations, local non-governmental organizations (NGOs), and international human rights organizations for more than a decade. In 2010 Human Rights Watch reported on this issues of FGM and had highlighted that FGM remains a serious problem in the Kurdistan region (Human Rights Watch, 2010; Saleem, Othman, Fattah, Hazim, & Adnan, 2013). In 2010, the prevalence of FGM was 78 per cent in Kurdistan (Human Rights Watch, 2010). In 2011, a new law was passed in Iraqi Kurdistan for fighting family violence in which FGM was considered illegal (Saleem, Othman, Fattah, Hazim, & Adnan, 2013). In Iraqi Kurdistan, as in other places in the world, FGM is seen by women themselves and by wider society as a practice that solely involves women, and is perpetuated by women. Mothers or other female relatives typically make the decision when and whether their daughters should be circumcised; midwives carry it

out; and the procedure is almost never discussed with the men in the family (Ahmad , 2001; WADI, 2012)

### *Eritrean communities*

Eritrea is a country that is located in east Africa, Eritrea was colonized by the British till the 1950s when they joint the United Nations granted Eritrea self-government within a federal union of Ethiopia. For 30 year Eritrea was in war with Ethiopia to become an independence county and in 1993 Eritrea gained its independence from Ethiopia. Eritrea has a population of 3.6 million with nine major tribes. Each tribes its own language and cultural. In Eritrea it is roughly half Muslim and half Christian. A larger number of Eritrean fled to Sudan during the war of independence in the 1970s and 1980s and other wave of Eritrean refugees fled to Sudan in the 1990s during a time of border conflict between Eritrea and Ethiopia. In their 1990s there was internal conflict with in Sudan that had a negative impact on the refugee population that was there so in 1994 Eritrean refugees began arriving in New Zealand. The total population of Eritrea refugees that arrived in New Zealand between 1995 and 2012 were estimated at around 367. They have resettled in two main areas Auckland and Wellington (New Zealand Ministry of Health, 2012). Like the other refugee groups Eritreans have poor health and this is a reflection of the circumstances from which they have come (Perumal, 2010).

Eritrean women are found at the lowest level of the social, economic and political structures. Young girls have from childhood been taught their roles as wives, mothers and homemakers (Zerai, 2003). They have not been told to cater for their own needs or work towards the attainment of their own aspiration. Their identity has been intricately linked to that of fathers or husbands. This had the consequence of Eritrean women being financially and socially more dependent. According to Zerai, (2003) the lifetime risk for an Eritrean woman dying from pregnancy related causes are estimated

to be one in fourteen women. FGM plays a major role in this as 89 per cent of women from Eritrea go through a form of FGM. According to U.S. Department of State (2001) the most commonly practiced forms of FGM in Eritrea are Type I, Type II and Type III. All of the women who are subject to any of the procedures one-third has been infibulated and both Muslims and Christians alike practice FGM (Zerai, 2003).

### *Indonesian communities*

On the other hand the Indonesia community come to New Zealand as migrants which mean that they choose to leave their country and choice to settle here in New Zealand (New Zealand Ministry of Health, 2012). Female genital mutilation in Indonesia can be date back to the 17<sup>th</sup> century, regional research studies that have been carried out have found that there was I high prevalence rate of FGM more than 90 percent females from Muslim families are cut by age18in some Areas (Newland, 2006). FGM in Indonesia is mostly Type I and IV (Irin News, 2010; Newland, 2006). In certain communities of Indonesia, mass female circumcision ceremony are organized by local Islamic foundations U.S. Department of State, 2001). There have been nationwide studies in 2003 found over 80% of the cases sampled involved cutting, typically of newborns through the age of 9 (USAID, 2003). In 2006, FGM was banned by the government; however, FGM/C remained commonplace for women in Indonesia - the world's largest Muslim nation (Irin News, 2010; Newland, 2006).

## **2.5 Global / local response to FGM**

### *Global response to FGM*

Over the past three decades there has not be much change in the prevalence of FGM in New Zealand and worldwide (WHO, 2008). Some of the challenges in

addressing FGM in New Zealand is lack of specific public health policy that sets guidelines to eliminate FGM and to address the medical and mental health issues arising from FGM practice. Another challenge relates to possible confusion in the terminology used to relate to FGM; especially given that different communities practice FGM differently and for different reasons (World Health Organization, 2008). Discussions around gender inequalities, health inequalities, the underlining context supporting or against FGM practice needs to be addressed (Ali, 2010).

The main international health goal that impacts on FGM is the Millennium Development Goals (MDGs), which arose from the United Nations Millennium Declaration and was agreed to by 191 member states of the United Nations in the year 2000. The MDGs are a set of eight goals that are to be achieved by 2015. The goals look at a range of issues that have an impact on the health a people all over the world. Some of the issues that the MDGs are trying to address are poverty, lack of education of women, child mortality and maternal health, HIV /AIDS and other diseases, environmental problems and global partnership for development (WHO, 2012). FGM is evident in three of the goals of the MDG, as set out below.

Goal 3 of the MDGs promotes gender equality and empowering women, (World Health Organization, 2003). Girls who have undergone FGM may be affected throughout their education based on the physical and psychological consequences of FGM. These consequences include preventing girls from attending school which in the long run leads to girls being disadvantage at all levels of education.

Goal 4 of the MDGs addressed the issues of child mortality and aims to reduce child mortality by two-thirds, between 1990 and 2015 targeting the rate of under-five mortality the focus is on under-five mortality rate; infant mortality rate; and the proportion of 1 year-old children immunised against measles (World Health

Organization, 2012). Goal 4 of the MDGs states that child mortality is another area that is affected by FGM. Child mortality can happen in many ways as FGM is sometimes performed on young girls and infants. With the many health impact is risk of death. One of the most common ways that child mortality occurs is that women who have undergone FGM have difficulties in child delivery. Studies have shown that FGM contributes to still births and neonatal deaths (Amnesty International, 2010; Abdulcadir, Margairaz, Boulvain & Irion, 2011).

Goal 6 of the MDG's is that of combating HIV/AIDS, malaria and other diseases. The practice of FGM is one that heightens the risks of HIV transmission in communities unsterilised tools are used (Amnesty International, 2010). An end to the practise of FGM is important for the achievement of MDGs 3, 4, and 6.

#### *Local response to FGM*

The practice of FGM is totally alien to New Zealand culture. Studies on FGM in New Zealand are limited; perhaps due to the fact that women with FGM have only been in New Zealand since the early 90's. Two FGM studies however, have been carried out by the New Zealand FGM education programme which involved Somali women living in Auckland (Denholm & Jama, 1997 & Denholm & Powell, 2009). The first, conducted in 1997, involved interviews with 88 Somali women. A follow-up survey was done in 2008, involving 70 Somali women. Findings from the first survey showed that nearly all of the women respondents said that health professionals did not know much about FGM. From the second survey in 2008 however, it was reported that there was an overall increase in FGM awareness among health professionals. Another finding highlighted lack of communication between Lead Maternity Carer (LMC's) and women with FGM. There was also an increase in women undergoing antenatal genital

assessment from 1997 (20%) to 2008 (80%). The survey in 2008, also showed that compared to their peers, women with a history of FGM were less likely to have ante natal care and a birth plan. 68 per cent of women with a history of FGM said that they did not discuss any birth plan matters with their health provider; while 80 per cent of them did not have birth plan; 80 per cent of them also reported not having any discussion regarding caring for scar tissues. There has been a higher rate of caesarean sections having being performed on Somali women with FGM in Auckland than any other ethnic groups given per natal issues (Denholm & Jama, 1997; Denholm & Powell, 2009).

Limitations of these studies were the use of self-reported survey which may include self-reporting biases and subjectivity in reporting their level of knowledge on FGM (Babbie, 2008). Within the Somali community, the topic of FGM remains a sensitive issue to discuss. Hence participants who took part in the survey might not feel confident discussing the issues of FGM and this may affect the way they answered the questions (Denholm & Jama, 1997 & Denholm, & Powell, 2009). As a result of the 2008 study. The New Zealand FGM programme developed guidelines for both health care and child protection professionals. Later these guidelines are used by many agencies. Some of the guidelines developed include FGM Clinical Care; Antenatal, Labour & Birth and Postnatal Guidelines (The FGM Education Programme, 2011).

## **2.6 Conclusion- A way forward for FGM**

There are some useful examples from the developed world of ways forward for FGM. Australia, UK and France are three of thirteen industrialised countries who have put in place laws against all forms of FGM being performed. However in addition to laws there are other effective tools that must be used in order to achieve the elimination

of the practice of FGM (Unicef, 2010; Moeed, & Grover, 2012). In Australia since the mid 90's there have been special health workers in hospitals, women's services and community organisations where they are funded to provide community education, strengthen knowledge about FGM and support change in attitudes in order to prevent FGM (The Royal Australian and New Zealand College of Obstetricians and Gynaecologists [RANZCOG]1997). Since 1996 there has been a National Education Programme on Female Genital Mutilation which has the primary goal of preventing the occurrence of female genital mutilation in Australia. The programme does this by providing a focus on community education, information and support; and assisting women and young girls who are at risk of FGM who live in Australia and also women and young girls who have been subject to the practice elsewhere. The National Education Programme on Female Genital Mutilation is funded by the Commonwealth Department of Health and Family Services (RANZCOG, 1997). The Department of Health in Australia has funded Family Planning in Victoria to produce a range of materials to improve health literacy, service access and planning regarding FGM. These resources have been developed to help both the communities that are affected by FGM and also providing health care (Family Planning Victoria, n.d.).

France was one of the first countries that has raised its concerns regarding FGM to the WHO in 1977 and is also one of the only countries that has convicted people for carrying out FGM on young girls (Smith, 2013). This makes the legislation more effective. There have been more than 40 FGM trials in France, and two practitioners and more than 100 parents have been convicted. Although female genital cutting is banned across the European Union, only a handful of cases have ever gone to trial in other European countries (Rowling, 2012).

In Britain it is estimated that there are over 660,000 women and young girls living with FGM. There are 15 specialist clinics in the NHS that offer a range of healthcare services for women and girls who have been subjected to FGM, including reversal surgery (National Health Service, n.d.) this could be used in NZ. Women will feel more confident in coming to the clinic as they perceive the staff to be knowledgeable and having undergone training to work with women who have experienced FGM (The FGM Education Programme, 2011). As noted earlier, there has been only one education programme, The New Zealand FGM programme that works with communities affected by FGM by health professionals. This programme however is not run nationwide and its services and activities are Auckland based only (The FGM Education Programme, 2011). Likewise, guidelines published by the New Zealand FGM programme for health care professionals antenatal, birth and postnatal care for women with FGM are not mandatory for all health services in New Zealand (The FGM Education Programme, 2011). Arguably not all health professionals in New Zealand cities and regions are well trained on how to care for women with FGM during antenatal and postnatal periods. Also the standard of practice and awareness is variable between clinics and amongst the staff of these clinics.

In New Zealand the FGM Education Programme does provide community training and use a training of trainers' model. Five communities affected by FGM practice were involved in some of these training sessions. The education topics focused on, developing knowledge on the adverse physical and mental health outcomes of FGM. It is hoped, that through education, women and girls are well informed on the harmful practice of FGM to allow them to make informed decisions. Community-based

empowerment programmes are also seen as an effective tool in addressing FGM in community. It is important for communities to play a large role in identifying their needs and fully participating throughout the intervention process creating long-lasting partnership as communities know their own issue and strategies (Ali, 2010). Future programmes therefore need also to address deficiencies in laws, regulation and programmes addressing FGM in New Zealand. People in NZ who are affected by FGM are mostly from refugee backgrounds. These are people who had to flee from their home lands not by choices. They were forced out by war or some have been victims of political terrorism. Thus they came to New Zealand with complex needs and histories of trauma or other mental health problems (The FGM Education Programme, 2011). Policies and programmes addressing FGM therefore need to be inclusive, creative and relevant to these populations. The practice of FGM is deeply culturally embedded complex and controversial. There are serious health consequences of FGM for women. However, preventing FGM is no easy goal. Also, provide a supportive environment for women experiencing FGM is a challenge for all developed countries.

## **Chapter 3: Research Methodology and Methods**

### **3.1 Introduction**

This chapter describes the research methodology and the research methods used in this study. Firstly the outline the approach and rationale for the methodology chosen will be described. Secondly, it will discuss the research methods for participant selection, the research setting, data collection and data analysis. Finally, the ethical considerations involved with this study will be discussed.

### **3.2 Methodology**

Methodology is the strategy that is used as a framework to carry out the researcher process, whilst method is the technique the researcher will use collect the data and analyse it (Taylor, & Francis, 2013). The theory being used for this research methodology is qualitative research, this theory informs the method used in this research study (Bernard, 2006; Payne, & Payne, 2005). Qualitative research is a research methodology that helps understand people's worldviews and their lived experiences (Bryman, 2012; Hesse-Biber, & Leavy, 2011). There are numerous qualitative methodologies that a researcher can choose from. However it is important that the researcher chooses the most appropriate qualitative method that enable him or her to answer the research question of interest. A qualitative descriptive methodology was used in this thesis to explore the stories of women living with FGM in Auckland, and to capture the strategies they propose for addressing FGM among the Somali, Eritrean, Indonesian and Kurdish communities in Auckland.

A qualitative descriptive methodology was used in this study as the most appropriate approach to explore the stories of women living with FGM in Auckland and to capture the strategies they propose for addressing FGM among the Somali, Eritrean, Indonesian and Kurdish communities in Auckland, as little is known about FGM in these different communities and so by using qualitative methodology, concepts

important to the communities could be explored. Qualitative research is the methodology that best fits with the communities that are being studied as most communities that are affected by FGM are communities from an oral based tradition (Denholm, & Powell, 2009). Qualitative descriptive study is based on the assumption that there is no one universal truth (Sandelowski, 2010). This approach provides more fully the richness and understanding of shared experiences and practices. The qualitative researcher is after depth in their data and analysis and interested in understanding social meaning (Sandelowski, 2010).

### *Methods*

Methods in the research are the step by step procedures and strategies for collecting and analysing the data that is gathered during the research processes (Babbie, 2008). In this research study two methods were used to collect the data: semi-structured interviews and focus groups.

Semi-structured interviews are common in healthcare research (DiCicco-Bloom & Crabtree, 2006). Semi-structured interviews are a type of interview format in which the interviewer has several key predetermined interview questions which are used to help define the areas that is being researched. Semi-structured interviews have the ability to let the interviewer or interviewee diverge from the topics put forward to explore new ideas or response in more detail (DiCicco-Bloom & Crabtree, 2006).

As their name suggests, semi-structured offer some structure for the interviewer, in comparison to structured interviews (Gilbert, 2001;Whitling, 2008). Structured interviews are a type of interview that has an interview schedule and in order to be reliable the interviewer maintains the order of questions asked. Questions that are on the schedule are asked word for word (Fraenkel, 2005). These types of interviews are often analysed using quantitative methods, such as frequency distributions (Smith, 2008).

Unstructured interviews can be described as informal interviews that are used for example by ethnographers when they attempt to integrate within another culture. Unstructured interviews resemble casual conversations and the interviewer does not have any question written down but they still guide the conversation (Fraenkel, 2005; Smith, 2008).

Focus group discussions are a very commonly used method in qualitative research. Focus groups are used for generating information on collective views (Doody, Slevin, & Taggart, 2013). A focus group is made up of people with similar interests or characteristics and allows participants to talk to each other about a certain subject. The method of the focus group is useful in generating a rich understanding of participants' experiences and beliefs (Kitzinger, 1995). The researcher is a facilitator and only guides the conversation rather than asking each participant a set of questions in turn (Doody, Slevin, & Taggart, 2013). The facilitator uses the group's interaction to gain information about a specific topic. The group is involved in collective activity such as debating and talking to each other (Gill, Stewart, Treasure, & Chadwick, 2008).

#### *Study location*

The research was undertaken in the Auckland region. The main factors which contributed to the decision to select the Auckland region was that it is the only city in New Zealand that community education on the issue of FGM is provided and thus participants could be recruited.

#### *Selection criteria and participant numbers*

As the focus of this research was based on the experiences of women who have undergone FGM the selection criteria focused on those women, over the age of 18 and

who had worked as community educators in the topic of FGM in Somali, Eritrean, Indonesian and Kurdish communities in Auckland. Female genital mutilation community educators were selected as participants in this study as the primary researcher believed that they would be more open in talking about FGM than community members who had undergone this procedure but who may never have discussed this topic previously.

### *Characteristics of the participants*

In this research a total of 4 women who are FGM community educator from communities that practices FGM participated in the study. The participants live in the Auckland region. Three of the four participants come to New Zealand under the United Nations High Commissioner for Refugees (UNHCR) refugee quota programme. The participants' varied in age the youngest participant being in her late 20's and the oldest being 50 years. The table below summarises the background information about the participates in this study. To protect the identity of the participants a pseudonym has been assign to each of the participants.

*Table 2: summarises the background information about the participate*

Participates pseudonym	Ethnic group	Age	Religion	Marital status	Children	language
Fatima	Somalia	20-30	Muslim	Divorces	4 children all girls	Somali and English
Soma	Kurdish	20-30	Muslim	Married	2 children 1 boy and 1 girls	Kurdish, Arabic, Persian and English
Rachel	Eritrean	40-50	Christian	Divorces	3 children all girls	Tigrinya, Arabic and English
Mia	Indonesian	40-50	Muslim	Married	2 children 1 boy and 1 girls	Indonesian and English

### *Recruitment process*

The participants in this study were recruited through posters (refer to appendix A) that were given to the leader of New Zealand FGM programme. It was known that have established links with community educators. Over the past seven years the primary researcher has worked as a community youth educator with the FGM programme and thus has personal contact with the programme leader. The New Zealand FGM programme director emailed community educators from each of the four ethnicities chosen in this study. This email contained the poster and the information sheet which outlined the purpose of the study (refer to appendix B). The information that was on the posters consisted of the purpose of the research, inclusion criteria, and the primary researcher's contact details. A two-week time period was given for participants to consider taking part in the study, and a date by which respondents should reply was included in the email that was sent out to potential participants. Those community educators interested in participating in the study, or who required any further information, were asked to contact the primary researcher.

After receiving the poster invitation, participants who wanted to take part in the study emailed the primary researcher (Ayan Said) to express interest in taking part in the study. The primary researcher contacted them via phone and they were asked their age and their role in their community in relation to FGM to fit with the selection criteria. As the study had two methods of data collection the participants were required to take part in both activities, and this requirement was outlined in the information sheet and consent form. Once the participants were satisfied with what the study was about and agreed to participate in both the semi-structured interview and focus group, they were given the consent form (refer to appendix C) Participants were selected on a "first come first served" basis, that is, those who first expressed interest in taking part in the study were chosen as participants.

### **3.3 Data collection**

The semi-structured interviews were conducted with four women community educators from the four communities separately at a mutually agreed time, date and in a private location. At the start of the interview the researcher outlined the process of the research and encouraged and gave time to the interviewee to ask any questions they had about the research and also reminded them that they could withdraw from the study at any point-up to the time of data analysis. The participants themselves determined the length of each interview, thus allowing for flexibility in the timeframe.

Four topics were developed to elicit a response from the participants. They were as follows;

1. From your experiences of listening to the stories of women who live with FGM in Auckland what themes and issues emerge?
2. How can FGM be addressed and effectively prevented among practising communities?
3. What barriers are there to preventing FGM?
4. What opportunities might assist in preventing FGM? (eg, useful sources of information)

All the interviews were digitally audio taped with the participant's permission. The digital recorder was placed in close proximity to the participant to ensure good sound quality. All the interviews were conducted in the English language as all the

participants had a good level of English. The researcher made hand-written notes during the interviews to help with recall in the writing up of the interviews.

The focus group was made up of the four community educators that participated in the semi-structured interviews. The researcher started the focus group off with an icebreaker to get the women all comfortable with each other and the group set some ground rules so that everyone was free and safe to share their views. Then the facilitator moved on to the purpose of the focus group discussion. The group discussion was recorded using a digital recorder. The digital recorder was placed in the middle of the table so that it could capture the conversation of the whole group and hand-written notes were also be made by the researcher and the discussion transcribed by a transcriber that was in employed for analysis.

The FGD was held at a community centre that was convenient for all the participants. It lasted about 40 minutes. As it was in the evening, dinner was provided before the focus group started, and this enabled participants' to get comfortable with the other members of the group.

### **3.4 Data Analysis**

In this study the data analysis which I chose to be most appropriate was thematic analysis. Thematic analysis is a method of data analysis which is used widely in conducting qualitative research. It is a method that creates and applies codes in a dataset. Braun and Clarke (2006), both describe the tool of thematic analysis as a way used in identifying patterns or themes in a dataset. Coding and analysing of the data is the heart of thematic analysis. In this research, the process of thematic analysis was carried out once the interviews and focus group discussions were both recorded and transcribed. The data that was found was arranged according to Braun & Clarke's set guidelines. The data was subsequently arranged into themes, which fit individual sets of

data and across different data sets. Upon completion of the coding process, themes which are found will be shown within the results chapter. For this research, an appropriate approach in conducting the research is that of thematic analysis as the aim is in exploring the experiences and stories of women who have undergone FGM within the Auckland region. From the research and data accumulated, strategies will be discussed to find ways in which the issues surrounding FGM are addressed. Thematic analysis provides an account of the data which is both complex and rich (Braun & Clarke, 2006). The researcher is required to move backwards and forwards amongst the whole data set in order for thematic analysis to work best. Extracts that are coded and of which are analysed and the data subsequently produced. An integral part of the process is writing which commences with phase one from noting down initial ideas, potential costs of research right down to coding and finally analysis process.

Thematic analysis according to Braun & Clarke 2006 is a process with six phases as described and listed below:

Phase 1- understanding the data, this process accrues by reading the interview and focus group discussion transcript. Braun & Clarke (2006) suggest reading the transcript twice or more to gain an understanding of the raw data collected. Once the data is familiar to the researcher, then the researcher can identify key themes and patterns from the transcript (Braun & Clarke, 2006).

Phase 2- This process involves identifying the primary codes in the data. The second part of this process is to categories the information into segments to make it manageable and easier to read. This is referred to as coding, coding is established from what is in the data and coding is data driven. According to Braun& Clarke, (2006) coding is carried out in systematic process through data sets and relevant data. This procedure is done manually by the researcher working through transcripts by allocating

each section of data with a code and number. The researcher is working on identifying key patterns and themes that were determined from the data (Braun & Clarke, 2006).

Phase 3- At this phase the codes have been identified and are put into initial themes. The entire data that is appropriate to the possible themes are collected; this process is carried out manually once the theme is identified within the transcript. This stage focuses on organising the codes into categories significant themes (Braun & Clarke, 2006).

Phase 4 – At this phase the researcher is reanalyzing and improving the initial themes that were established in the earlier phase. The researcher examines each theme to see if it works and if there is a substantial amount evidence to support it being a theme or if it needs to be reworked or refined into another theme. If there is not sufficient data to support it then the researcher has to reread the data sets to determine if the codes and themes identified match the data set and then modifying sub-themes if it is needed. A thematic map of the analysis is established at this phase, after the examination of the themes is carried out. The initial themes are rechecked to make sure they are accurate represent the data set (Braun & Clarke, 2006).

Phase 5- This stage involves three steps which are defining themes with support from data, identifying and refining the theme that were chosen earlier. By refining each theme this enables the researcher to create alterations before the final phase (Braun & Clarke, 2006).

Phase 6- The final stage in this process is the researcher produce a report. This would be based from the results of the thematic analysis (Braun & Clarke, 2006). The next chapter presents the findings for this study.

### **3.5 Ethical considerations**

Prior to data collection, ethical approval was granted by Auckland University of Technology Ethics Committee (AUTECH), for this research on 4th August 2014 application number 14/105 as shown in appendix D. Ethical considerations were identified and addressed as part of the research process. There are ethical considerations that were needed to be taken into account in order to protect and respect all participants. The participants were informed at the beginning of the interview and focus group that there would be free counselling sessions available to them at AUT on all three campuses if they required. At the beginning of the interviews and focus group discussion the participants were told that if uncomfortable at any point that they could ask the researcher to stop the recording.

#### *Informed consent*

Informed consent refers to when a participant has received adequate information about the research and is well informed to be able to freely choose to consent voluntarily to participate in the research. From the start the researcher made all participants in the study aware of the nature of the research by emailing the information sheet to the participants. The participants were advised about their rights to participate in the research or decline their participation at any time during the study, and which may include withdrawing from the research. The participants in this study were requested to fill out a consent form which confirmed their agreement to participate in the study.

#### *Confidentiality and anonymity*

In this study strategies were put into place to ensure that confidentiality and anonymity were maintained for the participants. The researcher had removed from the

transcripts all the identifying information of the participants such as names.

Pseudonyms were used to refer to the participants to ensure participants will not be identified throughout and on completion of the study. The participants did not use the names of other people when describing their experiences in the community to ensure anonymity of those people and any possible identifying information were removed from the transcripts also.

In this research to keep the confidentiality of the participant the consent forms were placed in a locked filing cabinet for the duration of this study and all of the electronic data was kept in a password protected computer to which only the researcher had access. The digitally recorded interviews were transcribed by the transcriber. Once the data was transcribed and checked for accuracy by the researcher the recordings were deleted. It was agreed with the thesis supervisor that a copy of the transcripts would remain in a locked filing cabinet at AUT for six years, after that time the transcripts and consent forms would be shredded.

### **3.6 Conclusion**

In order to get an accurate analysis of data for the study the researcher used thematic analysis as it is widely used in qualitative research. As we focused on the stories and experiences of women affected by FGM of whom are currently residing within the Auckland region the researcher found thematic analysis to be most appropriate as it helped me to create a strategy in which the issues regarding FGM are addressed by using the collected data. The researcher followed Braun and Clarke (2006) ideas that thematic analysis is a process which is divided into six phases from familiarising myself with the data set and studying the interview transcripts to searching for related themes and subsequently defining these themes. The last phase being number

six is where the researcher constructed a report based upon the data sets and information gained from the interviewees. The methodology which was used was that of qualitative descriptive methodology as the researcher found it well suited and appropriate to exploring the stories of the women of whom were affected by FGM within their own lives. These women came from various areas of the world such as Eritrea, Somalia, Indonesia and the Kurds. This chapter also discussed sampling, participant selection, data collection and data analysis, ethics issues were highlighted in this chapter. The next chapter describes the findings of the study.

## **Chapter 4: Research findings from the study of Auckland women living with FGM**

### **4.1 Introduction**

This chapter presents the findings from the study. The analysis for this research was based on the information provided from the individual interviews and focus group discussion. The questions asked aimed to explore the stories of women living with FGM in Auckland, and to capture the strategies they propose for addressing FGM.

This research used a set of semi-structured questions to guide the individual interviews and also the focus group discussion. The guide questions are as follows;

1. From your experiences of listening to the stories of women who live with FGM in Auckland what themes and issues emerge?
2. How can FGM be addressed and effectively prevented among practicing communities?
3. What barriers are there to preventing FGM?
4. What opportunities might assist in preventing FGM? (eg, useful sources of information)

It was intended that the focus of the interviews would be on experiences whereas the aim of the focus group discussion would be on strategies. However, the participants talked about experiences and strategies during both interviews and the group discussion. The women participants were very interested to hear about each other's stories and experiences and how FGM is practiced in their own contexts. One participant called after the FGD and said that it took away the stigma or sense of isolation felt by the women who had not had an opportunity to discuss FGM outside their own culture, and they found this interesting and empowering. As a result, the findings from the

interviews and group discussion have been combined together here. The structure of the chapter is in two parts: first, presenting and analysing the experiences; and secondly presenting and analysing strategies.

#### *4.2 The practice of FGM and women's FGM stories*

Although the question asked was not about their own experiences, women in the interviews and focus group discussion talked mainly about their stories of FGM rather than other women's stories. Also, they tended to talk first about what happened to them in relation to FGM in their countries of origin and then New Zealand. My view is that in the interviews they appreciated the chance to tell their story, give their history, and in the case of Fatima, it is possible that she identified more with me as a fellow Somali; hence her story was the most detailed.

The women talked about the different types of FGM that are practiced in their homeland as well as their personal experience. Fatima highlighted that in Somali culture,

Typically from our community back home it is the worst Type III (infibulation) which is also commonly called "Pharaonic circumcision" in Somalia girls are targeted at a young age to go get this procedure done this is between the age of 5 and 10. Some get it done as young as 2 years old due to the fact that if you are going to a western host country most parents know that it is against the law in most western countries. (Fatima)

Fatima told her FGM story in this way,

I was born and brought up in the city. I was born in a Muslim family. I went to a normal school in the morning and then in the afternoon I had to go to an Islamic school. I am the third daughter in the family and as a child my sisters and I did a lot of housework. As a daughter you are trained from an early age how to look after the family. No man is going to marry you, if you can't look after the home. This is your job; so I spent a lot of time cooking, cleaning and fetching water for the rest of the family. At the age of six, my mother took me to an area outside the city. A lot of the girls from my area who were the same age as me were at the little village that I was brought to. At the time I didn't know what I was there for: I was brought to be circumcised. One

of the girls from neighbourhood turned and said to me you must be really looking forward to this. As she was talking to me I heard the girl before me screaming. I was in shock. I couldn't move. This meant that the women from the village who come to support the woman circumciser had to hold me down. The women used a knife on me it was the most painful experience in my childhood. I was moving so much that she didn't do it right and a few days later I had to undergo the cutting again. The complications I experience due to FGM have stayed with me till this day.  
(Fatima)

Fatima said that she was 6 years old when she was circumcised and it is clear from her account that this was still a very memorable and painful experience for her.

Rachel, from Eritrea, had a different story to tell based on her own circumstances and the different customs in her culture. She noted that there are nine different tribes in Eritrea and each tribe practices FGM differently,

The most common types are Type II and III but in some tribes they practice FGM Type I and FGM is carried out within the first seven days after birth. (Rachel)

Rachel, being only 7 days old was circumcised with Type II FGM. She could not of course retell the experience. However, she could talk about her experiences subsequently, especially in relation to negative health consequences (described below in 4.2.3). Also, she did talk about the effect of FGM on her attitude towards her 3 daughters in that she was against them being circumcised.

The disadvantage about the health of women; it affects them from circumcision until they grow up. Even when they have babies, like the health issues, like during period time they have a lot of suffering. I understood the disadvantage for my daughters so I don't want them going through what I had. (Rachel)

In the case of Indonesian participant Mia (from the island of Java) she said that the most common type of FGM that is practiced,

Is only Type I in Indonesia; FGM is done “privately”, whereas for the boy we do the “mass circumcision. FGM in Indonesian is not the same as in African where they do damage to the female genitals. For us it is just to make a little bit of bleeding. To make it Sunna circumcision it is just a prick with I tiny drop of blood. It is believed that it will bring the girls good luck in life. (Mia)

Mia experienced Type I FGM in this reduced form (a prick of the clitoris to produce blood, as a new-born baby) and has been happy to have her daughter circumcised in this way. She did not describe any trauma relating to this experience for herself or her daughter. Mia did however mention that she had a friend, living in Auckland but from the island of Sumatra, who had experienced Type I FGM; in such a way that it involved removal of the clitoris. Again, this was carried out after birth, and she mentioned the link with psychosexual consequences such as a high divorce rate as a result of reduced sexual pleasure for women and men where there has been Clitoridectomy (complete removal of the clitoris).

Soma, the Kurdish participant, explained that Kurdish people talk about circumcision as if it was not a hard thing to experience,

It’s only a little bit, I have, I remember I have seen a girl they did it for, it’s only a little bit. They say we just want to take a little bit of it just to make things a little bit Halal, that’s it, and it’s not extreme like in African. I have seen...it was sewn together. (Soma)

However, she explained that the whole experience of having the hood of her clitoris removed was very traumatic,

Going through circumcision was very difficult for me as I was taken at night by my mother’s friend. She took me to a valley. I didn’t know what was happening. It was one of the scariest things I have ever been through. It was so painful because the knife the women were using was not sharp. Also the women didn’t say anything to us. Two women from the valley just held me down and just cut without a word. I didn’t know anyone. The lady that took me left and I was

scared. I was away from my family for two week. They cut me and I wasn't allowed to talk about it. This is the first time I have shared this with anyone. (Soma)

Soma said that it was very difficult for her to comprehend what had happened to her at the time. In the interview she said that she was very upset that she had had to go through this experience alone; whereas her four sisters had not had that experience of being taken out of the home by strangers. This happened to Soma in the context of ethnic cleansing requiring her family to move more than once to safer places. Thus, it was all a very traumatic time.

The participants came up with similarities and differences in their experiences in terms of Type of FGM, age of circumcision, setting and who took part in the circumcision. According to how the procedure was done, despite the different countries of their origin, some of the way the women described the cutting process included pain and emotional torment depending on Type of FGM. Where FGM was carried out at the baby stage clearly there was less obvious memory of the experience. In the case of Mia, the practice is more symbolic and less traumatic. Although evidence shows that when the procedure is medicalised there is a tendency for greater cutting (WHO, 2014). Thus, WHO agencies have a Zero Tolerance approach ever for symbolic practice (WHO, 2014). 'Not knowing' and a code of 'silence' around the events seen to be important elements of the trauma. The stories expressed in the interview setting were more personal and in-depth than in the focus group; and all interviewees said they were glad of the chance to tell their stories. In the focus group women were more interested in discussing differences in customs.

#### *4.3 Culture or Religions?*

FGM is interwoven in culture and religion. Culture can be described as being a set of traditional, events, ideas, values and beliefs that a group and individual people

have (Whitehorn, 2002). All of the participants described their cultures beliefs as having sustained the practices of FGM and therefore as a barrier to prevention.

Fatima stated that she thought that Somali people,

Trying to hold your culture as much as you can when it comes to a foreign place...like especially in the Somali community because we don't integrate well with other people most of the time.  
(Fatima)

Fatima went on to describe,

People practice because I think in the Somali culture we just don't talk about it in a big generalised way like we think it affects us like and it's only our problem.... The practice of FGM is strongly valued; it's been around for thousands and thousands of years. (Fatima)

Soma said that in Kurdistan,

It is the same culture all through so FGM can be found in all parts of Kurdistan. (Soma)  
It's culture but they blame it on religion .....I think it's only culture. (Soma).

Mia stated that

In our culture FGM is quite common, I am of Javanese culture. On other hand, FGM is not something quite important in my culture but I don't know in a different Island. (Mia)

Mia went on to said that FGM is something that,

It is a culture problem (Mia).

Rachel from the Eritrean community member said FGM is needed to ensure that young girls are able to get married,

Because in our belief when they get married....a girl she have to stay a virgin, this is a culture and a religious view that is held by some of the community. (Rachel)

In Eritrea Type III is practiced involved the seeing of labia which is only cut open at manage. In Eritrea religion is a mix of Islam and orthodox Christianity with FGM practiced regardless of which religion people belong to. FGM is an ancient tradition that is deeply engrained into culture and religions. FGM is associated with women's social status, family honor and pride that are associated with marriage.

Religion plays a role in preserving and empowering the practice of FGM (Berggren, Bergstrom, & Edberg, 2006). FGM has been practised by many different religions such as Muslims, Catholics, Jews and other ancient religions. The practised of FGM predates religions including Islam and Christianity. All of the participants in this study highlighted that religion is a belief that people in their communities hold as a reason that FGM needs to be carried out. The community views it as practicing their Muslim faith (Cummings-Knight, & Hussein, 2014). The participants stated that there is no basis in any of the religious scripts that said anything about FGM.

Soma said that in Kurdistan the majority of the population is Muslim but there are also Christians and FGM is practice by all, Soma also said that FGM is something that transcends all religions.

Mia noted that Indonesia is similar to the Kurdish community as the practice of FGM transcends Indonesian religions,

It's not really something religious ....but some still believe that it is a  
religious practice. (Mia)

Rachel, the Eritrean participant, said;

It doesn't tell in religion, it doesn't tell... it is just belief not about religion ...for old people it is  
a little bit hard to change them because...they believe it is a religious reason. (Rachel).

Rachel also went on to say,

In our belief when they get married....a girl she have to stay a virgin...this one is most priority so a girl in order to stay a virgin she has to circumcise also we believe this one...if she don't do circumcison that means she can go easily to men....and yea she can do any her desires...because we have this belief...everyone think or everyone understand circumcison for girls are most important in order to keep their virginity. (Rachel)

The Somali participant Fatima stated,

It's religious and so for many centuries now people just believed the religious content. (Fatima)

Religious leaders take varying positions in different countries with regard to FGM: some promote it, some consider it irrelevant to religion, and others contribute to its elimination. Generally, Somali religious leaders heavily support it on the basis of religious theory. Fatima talked about non-Somali leaders saying,

The Islamic Sheikh saying that it wasn't actually religious that there is no quotation in the Quran. (Fatima) But this is different for Somalia.

The three Muslim participants in this study highlighted that there is discussion around FGM in the religion required by the Islamic faith as some of the participants talked about the link between FGM and its association with female sexually. They talked about how in their communities FGM is seen as a religious requirement. One of the participants said,

It is from religion long time ago.....It is called Sunna which is just a cut on the top of the clitoris; Sunna refers to practices undertaken or approved by the Prophet and established as legally binding precedents. (Fatima)

Thus, religion and culture are so entwined that it is difficult- especially given the long-term nature of the practice- to separate them.

#### *4.4 Health consequences*

The damage to and removal of healthy and normal female genital tissue interferes with the natural functions of girls' and women's bodies. All the participants talked about the immediate complications that women and girls who have undergone FGM experience; that is, pain and bleeding as a consequence of the procedure. The procedure itself is traumatic as girls are usually physically held down during the procedure. The tools that circumcisers use for circumcision are often not cleaned and are therefore not sterile resulting in long-term complications.

Fatima highlighted that,

It was very hard, you know like, I never could play sports, you know even with my periods it took me a lot longer, sometimes I had my period for three weeks, so it was just...very hard on me being completely sewn up, which has more health implications, so that's why you hear a lot more stories about people being pregnant or some people not actually being able to get pregnant in our community. (Fatima)

Soma the Kurdish participant stated;

That going through FGM caused a lot of pain, bleeding and stuff and she knew people who had died from undergoing FGM (Soma).

Mia from Indonesia highlighted,

That as people in Indonesia go through Type 1 FGM and there are no real health issues that have been shown for going through Type I. (Mia)

Rachel the Eritrean participant discussed the health issues that she has gone through.

Health is important to everyone...I felt a lot of pain I had a lot of health issues with my circumcision.....I have had a lot of urine infection...I had difficult time with delivering my first baby that is why I believe that circumcision is harmful for women. (Rachel)

Rachel went on to talk about the long term health issues,

During period time they have a lot of suffering and when they have a baby...that's another one...even sometimes when they have FGM Type III, like Type II also when they go...to the urine they have difficulties. (Rachel)

The long-term consequences that the participants talked about in the interview included recurrent bladder and urinary tract infections, reduced sexual pleasure, an increased risk of childbirth complications one of the participant in the focus group described how she had difficulties in childbirth she said,

I was in a prolonged labour, I couldn't give birth because my cervix was too small because of the FGM..... My cervix had refused to open..... I got scared because it was my first child, then the blood pressure went high...and they had to do emergency caesarean. (Fatima)

Fatima shared with the group how she,

Almost die for because I was over-bleeding Women with FGM are at a greater risk than women without FGM for an obstructed or prolonged labor. (Fatima)

Fatima shared also shared with the group how FGM has impacted her sexual intimacies with her husband, she went on to say,

When you want to be intimate with your husband it is really hard, it is really painful, it's just like you're an eighteen year old girl... I am almost thirty now..... but I feel like a twenty year old, a virgin Sometimes when we are not intimate for two weeks or two months it just come back to square one...I have to use warm water...salt water it's so painful I cannot even urinate eh...it is very hard for me...especially for me. (Fatima)

FGM is associated with psychological and psychosomatic health complications the participants described feeling fear before and during the procedure, they also talked about the loss of trust

As the people you trust the most are the ones that took us to get the procedure done.....I knew what was happening to me but...I just wanted it to be privacy....who should I blame? I can't blame my mother...because my mom also she had to go with tradition otherwise she going to be the laughing stock in the community. You know when it comes to Somalian community, so the FGM has to be there. When a parent go deeply into traditional...you know you have no voice, you cannot talk is your world against you...you have no choice. (Fatima)

#### **4.5 Experiences of FGM in New Zealand**

##### *Community attitudes towards FGM in NZ*

FGM is a practice that has been around a long time. Attitudes towards FGM amongst the community that have taken part in the study vary greatly. People feel torn between their knowledge of the harmful consequences of FGM and the social and cultural pressures to continue the practice. In this study only one participant expressed support for FGM and said that she only supported Type I which is the minor type and the one that is not associated with really harmful health consequences.

Rachel said that,

In NZ the Eritrean community we are small community, they're happy for their children...they didn't do FGM. (Rachel)

She went on to say that,

Before she was educated on FGM she not feeling relaxed. I was thinking about my kids. I am happy, my children they don't circumcise. (Rachel)

Fatima the Somali participant highlighted that FGM is not a topic that is open discussed.

She said,

We never really used to talk about FGM. I think everybody knew if anybody didn't have it done, but in terms of talking about it, it wasn't open communication. (Fatima)

Soma the Kurdish participant also highlighted that 'silence' around the issues of FGM.

She stated that,

It's really secret. It's really secret, they don't want others to know they've done it or they want to do it for their daughter. (Soma)

On the other hand Mia the Indonesian participant talk about how easy it is to talk to her community about FGM she said that,

It is still privately talked about, but is still easy quite. (Mia)

To engage the community in talking about FGM she also added that as long as it is not talked in the front of a man, there is open discussion and for her she finds it easy.

### *Health care professional's attitudes*

The attitudes that health care workers have towards women that have undergone FGM can have an impact on the trust and communication that women will have with the health system. The health care providers' beliefs and values are reflected in their communication and can have a negative effect on their interaction with the women who have been subject to FGM. In this study only Fatima the Somali participant shared her experiences of the NZ health care system.

Fatima described giving birth to her first child in Hamilton. She started off by saying health care providers knowledge about FGM was varied,

when going to the hospital for my first like check-up and like even for me to talk to my midwife about what's wrong was very, very hard like it's not an easy thing to do because at that time you

still don't know you're different, like you think you're the same like everyone else. So when I started seeing like nurses and doctors coming around and looking at me like a weird object it made me feel like I shouldn't be there. I didn't want to be looked at like I had done something wrong just because I wasn't normal in the Western society but it was very much normal back home. It make me feel like I couldn't go to hospital and get check-ups regularly, or talk to my midwife about it..... I didn't know this procedure had a big impact on. (Fatima)

Fatima went on to say,

My midwife asked me to get defibrillated, which at that time I didn't know what that meant, I did not know that my FGM or my procedure for FGM had an impact on me, it was just very hard to actually tell my doctors.....that say yes because I didn't know what they were cutting and then I didn't believe it should be cut, like you know, so then when I talk, my mom about it my mom said you don't do it do you go through two pains when you do through just one like the both of it. But at that time I didn't know the impact it would have on my delivery you know like....when I became like an FGM educator then I saw Oh my God like I made one of the biggest like the biggest decisions of my life. Because how bad if I wouldn't have gone to the hospital unit too late. Like the de-infibulated process is very important but at the same time, I think it's still understanding that communication between the doctor or the midwife and the patient and like when I have seen the visual pictures of women dying whilst giving birth because their babies can't come out that shocked me because I could have been one of them people. (Fatima)

Fatima chose to become an FGM educator through contact with a FGM educator. She is glad that she had her awareness raised as it helped her to protect herself and female family members.

My first pregnancy I can say was highly difficult for me, because after my first pregnancy getting cut I didn't really get re-circumcised... I just left it and after that I realised there was a tremendous difference in my life, after that like.....I didn't like, I wouldn't be gone from my child for too long...like going like even going to the toilet, I felt like there was something wrong with me peeing normally for the first time.... Because I felt like everything was coming out too fast and I was done like in 30 seconds...so like that really shocked me, like the fact that I could be in the toilet for 30 seconds...like other girls, but I didn't know that that caused their problem

as such so.... The health care system I feel like....does need a bit of educated on because at that time it make me feel really upset going to the hospital and seeing that the doctors didn't understand me. (Fatima)

Fatima had a difficult delivery experience because of prolonged labour and associates this with the poor knowledge of the midwife and not having an appropriate birthing plan. So, Fatima was expecting to be re-sutured after delivery, as happens back home. But, this is not the practice in NZ as it is illegal and against local professional ethics. This upset her, but in the long run, having got are her shock, she was glad of the benefits she calls for clear communication on all these issues.

#### **4.6 Suggestions for addressed and effectively preventing FGM among practicing communities in NZ**

##### *Education*

Education is a key theme in effectively prevent FGM in practising communities (WHO, 2008). All the participants saw education playing an important role in addressing FGM.

Fatima the Somali participant said that,

Education does work but I think education takes a long time to work....education did help me to understand the risks involved with FGM. (Fatima)

Rachel the Eritrean participant said that for her community education is the way to go to make change,

Education was quite helpful.... they talk about the different types of FGM and the disadvantage about the health of women...this shows the women that it is an ongoing thing in their lives the education session I felt like the women learn a lot. (Rachel)

Rachel also highlighted that,

It's hard to change what they're growing up...within two or three lessons...it takes time.

(Rachel)

Soma the Kurdish participant said that she felt that there needed to be more education,

We need more of those to educate especially, to educate people yea if they go back and to educate other people. (Soma)

Mia the Indonesian participant said that she,

Well, I think educate them it the most important why to make changes. (Mia)

### *Laws and legislation*

The participants in this study suggested that an effective way of preventing FGM was through laws and legislations as FGM is illegal in many countries. Having laws and legislations can help stop the practices of FGM. As FGM is such a private thing it can be a bit hard to implement and enforce law but the participants in this study thought if people know that they can have criminal proceedings brought against them then they would be less likely to carry out the practices of FGM.

Mia talked about how in Indonesia that there is a law but it is not really strict. She said that there is government policy, a policy that no one can really push you to have FGM. She also pointed out that by having a law or legislation it could also have a negative impact on people who really want to carry out FGM on their children. It can forces then to go to,

People do it in the black market, black market nurse or black market doctor that you never know their qualification. (Mia)

Soma the stated that there is a law in Kurdistan which means that the ladies that carry out the procedure of FGM are doing so illegally The Documentary ‘A Handful of Ash’(Ahmad , 2001).Although there is no law in Somalia there is a law in New Zealand and Fatima said that because of the law people know that they cannot perform FGM on their children. She said the people view FGM as being,

Nobody’s business, it’s no big problem but now there is a bigger thing out there where there is the law, they can actually go to jail for doing this. (Fatima)

Rachel the Eritrean participant said that in her community,

If everyone knows about the law...it says do this stuff...this one is against the punishment may be some people they fear the punishment, so that might stop it. (Rachel)

Rachel also said that people,

Feel scared if I do this one I will get in trouble, so law is also helpful because everyone also...they have to understand. (Rachel)

#### **4.7 Conclusion**

The discussion on strategies was quite short as the participants knew mainly about education through personal experience. They also knew about laws against FGM and were fearful of going to jail. I initiated a discussion of rights and prevention of FGM, but participants were unfamiliar with this notion. In the next chapter I will present a summary of findings, and implications and recommendations for action.

## **Chapter 5: Discussion and Recommendations**

### **5.1 Introduction**

Based on the interviews and FGD with the participants, FGM can be seen as a traditional practice that is deeply embedded in the culture of the women's communities. Chapter Five concludes the thesis by presenting a discussion and recommendations in relation to the findings that set out to answer the research questions:

1. From your experiences of listening to the stories of women who live with FGM in Auckland what themes and issues emerge?
2. How can FGM be addressed and effectively prevented among practising communities?
3. What barriers are there to preventing FGM?
4. What opportunities might assist in preventing FGM? (eg, useful sources of information)

The findings from the research highlighted some general themes and these were presented in Chapter Four in sections titled: the practice of FGM and women's FGM stories; experiences of FGM in New Zealand; and suggestions for addressing and effectively preventing FGM among practicing communities in New Zealand. Finally, based on the discussion and findings a number of recommendations are made for preventing FGM in the Auckland contexts.

## 5.2 Summary of the findings

### *The practice of FGM and women's FGM stories*

In fact, the participants in the interviews and the FGD concentrated mainly on the first research question; and particularly telling their own stories, with more limited attention to questions 2, 3, and 4. It appeared to me that they wanted their stories to be heard, and they had had little opportunity to voice their experiences. It may also be that it is because FGM has had such a great effect on them (especially for the Somali, Kurdish and Eritrean women); it is important in terms of the cultural benefits to them; but also because of the decisions they have had to make about their daughters and other members of their family. This fits with the literature which refers to the hidden and silenced nature of FGM with many women unable to speak about their stories (Berggren et al, 2006; Naughton, 2013; Dean,2014).

The practice of FGM is common in many countries, including those featuring in this research. I looked at four communities living in Auckland that come from such countries. Type I and II are the most common forms of FGM performed in most countries; including Eritrea and Kurdistan, with Indonesia practicing Type I only (Unicef, 2010; WHO, 2008; WHO, 2010). As identified in the literature on Somalia the predominant practice is Type III (Unicef, 2010; WHO, 2008). The experiences of the four participants in this study matched with the literature showing that they all had experienced the type of FGM common to their country.

Beyond their own stories they did mention the issue of the next generation of women; in particular FGM for their daughters. Yet, there was a tension expressed between their happiness that their daughters would not suffer as a result of being circumcised; and concern that not having been circumcised may negatively affect their chance of marrying within the community. Also they expressed worry, about the norms of sexual freedom within the wider society being a bad influence on their daughters'

behaviours and the lack of perceived controls on this which typically is seen to be provided by FGM.

### *Culture or religions?*

The participants debated issues of culture and religion but essentially they seemed to view FGM as more cultural. They said that it was something that people struggle with because of the interwoven relationship of both culture and religion. In communities that practice FGM it gives a chance to women to be eligible for marriage and bearing children. The practice is the main social security women have (Denholm,2004). This still applies within Auckland communities today. This may be perhaps because these communities are small and new to New Zealand (only now are the first generation reaching adulthood) and are thus still dominated by traditional norms.

The traditional norms of practice societies, as discussed in the literature review, are based on patriarchal customs (Briggs,1999; Denholm,2004 ;Jones, Ehiri,& Anyanwu,2004; sman, Mahmoud Warsame, Johansson,Fried,& Berggren,2013;). Resources such as land and other economic resources are under male control and the only way that a woman has access to any resources is through her husband. In order for a woman to be eligible for marriage it is essential that she is a virgin. The association between virginity and FGM is very strong. Virginity is an absolute pre-requisite for marriage. This also links with family honour. If a woman loses her honour, the entire family is dishonoured. The most dishonourable experience for a man is the sexual impropriety of a female member of the family. A girl that has not undergone FGM has no chance of marriage within her community, regardless of her virginity. Her access to land and future resources are therefore dependent on her having undergone FGM. The women in this study all had daughters and they made it clear in the discussions these issues of traditional norms are still very important to them.

### *Health and psychosocial consequences*

The findings provide further evidence (Andro, Cambois, & Lesclingand, 2014; Reisel, & Creighton, 2015) that the practice of FGM causes considerable consequences for women and young girls psychological and physically. The physical and mental health of the women who have undergone FGM has been well documented in the literature as discussed in Chapter Two (Mulongo, Hollins Martin, & McAndrew, 2014). In this study the women who could remember their procedure talked about the devastating physical experience of FGM at the time it occurred, and how it affected them then, and in relation to the long term consequences. For these women there were clear negative health and psychosocial consequences.

The literature refers to the event itself and the consequences of FGM (Berggren, Bergstrom, & Edberg, 2006; Lundberg, & Gereziher, 2008; Thierfelder, Tanner, & Bodiang, 2005; Upvall, Mohammed, & Dodge, 2009). This is mirrored here in the study for those who remembered the experience. For those participants circumcised at a young age they do not have a story to tell and thus are not really aware of the health consequences at the time. FGM is traditionally carried out by elderly women of the village who are specialist in this task, (ie traditional birth attendants (TBA), usually without anaesthetics and with crude instruments; this was the case for two of the participants. The study showed that this crude and non-anaesthetized experience contributed to the trauma; and this is in line with the literature which indicates that the experience is made worse by the circumstances (Utz-Billing, I. I., & Kentenich, 2008; Mulongo, Hollins Martin, & McAndrew, 2014).

The literature also refers to the long-term impact of FGM (Andro, Cambois, & Lesclingand, 2014; Reisel, & Creighton, 2015), and this is demonstrated here in the findings where the women tell stories of the effects it has had on them in their adult

lives. For the Eritrean participant although she was circumcised at an early stage and has little memory of this, it did have long-term consequences which she talks about. From the studies that have been conducted, long-term complications for FGM include: psychological trauma and flashbacks; post-traumatic stress disorder; painful intercourse; and pain and chronic infection from obstruction to menstrual flow. The women in this study talked about some of these issues in relation to long-term complications that they have faced and clearly indicated that these were issues for them and other women in their communities in Auckland.

### *Experiences of FGM in New Zealand*

#### *Community attitudes towards FGM*

The participants felt that there were both positive and negative attitudes towards FGM in their communities with small size cited as an advantage; the smaller the community the easier attitude change can occur. However, it was also noted that FGM in communities in Auckland is not openly discussed. This limits the scope for changing attitudes and as mentioned earlier, traditional cultural norms still dominate community attitudes, placing an additional challenge for change.

#### *Health care professional's attitudes*

In this study only one of the participants, the woman from Somalia, shared her experiences of New Zealand health workers. This was mainly because she had delivered her first child in New Zealand and had much to say on the subject. Her experiences were similar to those documented in the literature; she had similarly negative feelings of being rushed, not having things clearly explained to her, and having different health workers attending her, whereas in her country she would have had one health worker (Berggren, Bergstrom, & Edberg, 2006). In another study woman talked about feelings of shame and described a fear of being not accepted, and women felt embarrassed (Denholm, 2004;

Denholm, & Powell, 2009). This was similar to the experience of the Somali women in relation to the delivery of her child in New Zealand.

*Suggestions for addressing and effectively preventing FGM among practicing communities in New Zealand*

*Education*

Participants all agreed that educating people about the disadvantages of FGM is important. It helps people to examine their own beliefs and values related to the practice in a dynamic, open way that is not experienced or seen as threatening (Dawson et al ,2015; Finke,2006; Jacoby,Smith,2013; Moeed,& Grover, 2012). The participants, whilst supporting education, did not suggest in detail different educational strategies. This may be because of the volunteer nature of their role in relation to peer education. Also, it may be that given that they were older women they were somewhat removed from new ways of looking at education. However, their support for education shows the potential for this to be an important strategy.

*Legislation*

The literature notes that a legal framework cannot stop FGM unless there is strong implementation, enforcement and prosecution, though such laws are difficult to enforce (Dustin 2010; UNICEF, 2010). In this study having effective laws against FGM in New Zealand was seen as a positive thing because it can act as a deterrent to young women being taken overseas for the purposes of circumcision, and creates a disincentive that people will not ignore because of fear of prosecution. However, they did also note that the presence of laws against FGM can drive the practice 'underground' for reasons of that fear of prosecution.

### **5.3 The way forward: A Culturally-appropriate Human Rights approach to end FGM?**

Migration to western countries from countries known to practice FGM over the past four decades has meant that the practice is a concern in new places of settlement, including New Zealand. It is hard to know the exact nature and extent of the problem in western countries for a range of reasons such as the private nature, cultural taboos, the hidden nature of the practice and the fact that FGM is illegal.

FGM plays a vital role in a woman's life from defining gender, women's status and self-identity in their communities. International institutions against FGM, such as the UN and WHO just to name a few, state that FGM is a violation of human rights (UNICEF, 2010 ;WHO,2008). During this study the issue of human rights was brought up by the researcher; yet it seems to me from the discussions that the participants of the study did not view human rights as a way to end FGM; if they thought about it at all. Women from practicing communities typically argue that it is an important part of their cultural heritage or their religion. I consider that as FGM is embedded in cultures that women hold dear (and refugee communities have lost so much of culture in their lives) they struggle to see it as a rights' violation.

However, I do believe that a rights based approach can provide a framework for government and policy makers to address the issues of FGM. The table below highlights all of the international conventions that are applicable to FGM. These show that there is a weight of policy and legislation globally to prevent FGM, but implementing action is an ongoing challenge and requires a culturally sensitive approach to rights.

*Table 3: International by binding instruments applicable to FGM*

Legally binding instruments	Non- legally binding Instruments
<ul style="list-style-type: none"> <li>• International Covenant on Civil and Political Rights (1966)</li> <li>• International Covenant on Economic, Social and Cultural Rights (1966)</li> <li>• Convention on the Elimination of All Forms of Discrimination Against Women (1979)</li> <li>• Convention on the Rights of the Child (1989)</li> <li>• European Convention for the Protection of Human Rights and Fundamental Freedoms (1950)</li> <li>• American Convention on Human Rights (1978)</li> <li>• African Charter on Human and Peoples’ Rights (Banjul Charter) (1981)</li> <li>• Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Women in Africa (2003)</li> <li>• African Charter on the Rights and Welfare of the Child (1990)</li> </ul>	<ul style="list-style-type: none"> <li>• Universal Declaration of Human Rights (1948)</li> <li>• General Recommendations: 14 (1990), 19 (1992) , 24 (1999) of the Committee on the Elimination of Discrimination against Women</li> <li>• Committee on Economic, Social and Cultural Rights, General Comments 14 and 16</li> <li>• Human Rights Committee General Comment 28 Committee on the Rights of the Child General Comments 4, 5</li> <li>• Declaration on the Elimination of Violence against Women (1993)</li> <li>• General Assembly Resolutions: 56/128 of 2002, 61/143 of 2006, 62/133 of 2007, 63/155 of 2009</li> </ul>

Sources: (UNICEF, 2010)

Since FGM has come onto the world stage there has been a lot of debate surrounding the issues. There are those who believe it is a cultural practice that should be left alone as the communities the practice, it should determine what is in their best interests (Affara,2002;Anand, Stanhope,& Occhino, 2014;Callister, 2011; Guzman,2011).On the other hand there are people who believe that FGM is a practice that is a violation of human rights( Guzman,2011). Since the early 80s an anti-FGM

movement has been working to end FGM using a human rights framework with an emphasis on the rights of children and women (UNICEF, 2010).

The concept of human rights is centred on a western ideology, the constructed universal norms that all individuals are entitled to rights. This system works well in societies that are based on the right of the individual first and the group or whole as second (Callister, 2011; UNICEF, 2010). For example, FGM has been described as a horrific exploitation of women's bodies (UNICEF, 2010). However, this universal individualized way of thinking does not translate into a universal system for societies which are oriented by group first or religion/ culture first and individual second. Thus, the human rights framework, based on a western-centric model, does not resonate with many country contexts where FGM is practiced which have very different historical and philosophical norms.

I argue that FGM is a human rights' violation when it is performed without the consent of the girl. The intention of parents is not to harm their daughter as decisions about FGM are often made out of love and to seek the best outcome for their child. I support a much more culturally appropriate and community focused rights based approach to addressing FGM.

#### **5.4 Implications for FGM prevention in New Zealand**

The participants in this study made recommendations broadly related to education. Having undertaken this study, drawing from their comments, the literature, and my own experiences, my recommendations for practice are:

## *New Zealand FGM Education programme*

The New Zealand FGM Education programme has played an important role to date. However, the current emphasis of one education campaign annually is insufficient to influence change. Currently the programme is engaging with five practicing communities; but it is important for them to expand into other practicing communities such as the Egyptian and Afghani diaspora.

Specific recommendations for increased actions are;

- Providing an evaluation report to the community educators so that the educators know the success of the programme, what occurred during the programme, what worked well and what did not work so well.
- Making videos of community education being undertaken with all groups; education is done in gender groups and the use of videos for each of the groups give opportunities for them to hear each other's views.
- Having space where religious leaders can create open discussion about FGM and Islam.
- Facilitating inter-generational dialogue.
- Specific activities addressing the lack of clarity surrounding Type I/ Sunna - This would involve FGM educators developing specific initiatives focusing on health impact and religious beliefs about Sunna. The association of Sunna with FGM gives it religious legitimacy which needs to be debated.
- Where health care providers work with practicing communities they should undertake FGM training, including the cultural context of FGM; clinical care of women with FGM (including De-infibulation care); and culturally appropriate sexual and reproductive health education

### *Other Initiatives in New Zealand*

Community-based empowerment programmes are also seen as an effective tool in addressing FGM (Judd, Frankish, & Moulton, 2001). It is important for communities themselves to play a large role in identifying their needs and fully participating throughout the intervention process creating long-lasting partnerships as communities know their own issues and ways of addressing these issues (Ali, 2010). Raising awareness is about increasing the level of knowledge surrounding a particular issue and its impact on society. Raising awareness that FGM is a health issue within practising communities can be done by holding meetings, discussions and workshops and doing this over a long period of time to create behaviour and attitude change. Also important would be the creation of a network of community educators that can support each other and share ideas, and also a network of health care providers who know about FGM.

### *Initiatives which relate to communities practicing FGM outside New Zealand*

The role of communities back home is also important. As this thesis has highlighted the complex mix of socio-cultural factors and combination of beliefs, religion and social acceptance contributes to the continuation of FGM. These values are also held onto strongly because of the loss that refugees have faced. Below are some of the successful strategies used to reduce the practice of FGM internationally (Mathews, 2011)

- Government and non-government agencies working alongside religious leaders, societal leaders and health professionals to deliver education on FGM to the community.

- Using culturally and linguistically appropriate methods of communication with the community, including theatre and role-play, to heighten awareness of the issues and catalyze self-starting cultural change.
- Involving men and community leaders in these educational and awareness-raising efforts (including facilitating conversations between men and women who have suffered FGM).
- Education of young girls (since mothers play a major role in FGM of their daughters).
- Promoting awareness of key human rights' instruments (Mathews, 2011).

### **5.5 Limitations and benefits of the research**

This study was carried out as part of a post graduate qualification, for the Master of Public Health, and hence all parts of the research process were subject to time constraints. All the participants in this study were from culturally diverse backgrounds adding richness to the study and reflecting the incredible diversity of Auckland's population. The topic is one of cultural and personal sensitivity so this added to the challenge of undertaking the research. But, the fact that I belong to a practicing community- that of the Somali- and I am an FGM educator greatly facilitated this study. It would also be beneficial in future to go in-depth into different cultures living in New Zealand in relation to this topic. As a new researcher this was an exciting process, and as an experienced FGM educator it was a challenging and rewarding experience for me adding to my skills and understanding.

### **5.6 Conclusion**

FGM is an area of health which needs to be explored in various contexts including that of New Zealand, as there little research on women's experiences and community viewpoints. Despite decades of prevention programmes and global rights

based legislation and targets there has been little shift in FGM prevalence internationally (Unicef, 2010). This thesis argues that there is a need for strategies to prevent FGM that use a more culturally appropriate and community based approach, moving beyond global statements. These strategies also apply to the New Zealand context, which needs to take into consideration the diversity of FGM practicing communities.

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## **Appendices**

**Appendix A: Poster advertising the research**



# Participants Invited

Your participation is invited for a project looking at the Perceptions and strategies of women living with Female Genital Mutilation among the Somali, Eritrean, Indonesian and Kurdish communities in New Zealand.

If you are wanting to participate or want more information, contact Ayan on [Kqt9850@aut.ac.nz](mailto:Kqt9850@aut.ac.nz)



## Appendix B: Information Sheet

### Participant Information Sheet



Date Information Sheet Produced: 8 April 2014

#### Project Title

Stories and strategies of women living with Female Genital Mutilation among the Somali, Eritrean, Indonesian and Kurdish communities in Auckland.

#### An Invitation

As-salamu alaykum and Warm Greetings

My name is Ayan Said and I'm from Somalia. I'm a health promoter with a special interest in refugee and migrant health and women's health issues such as FGM. I am currently working on my Master's in Public Health at AUT. You are invited to participate in a research project exploring perceptions and strategies of women living with Female Genital Mutilation among the Somali, Eritrean, Indonesian and Kurdish communities in New Zealand.

#### What is the purpose of this research?

The purpose of this research is to explore the stories and strategies of women living with Female Genital Mutilation in Auckland. The four communities this study is focused on are the Somali, Eritrean, Indonesian and Kurdish communities in Auckland. This research project is part of a qualification in Masters of Public Health. The information gained from this study will provide first-hand information about the stories and strategies of women

living with FGM among the Somali, Eritrean, Indonesian and Kurdish communities in Auckland. This may help you and others in your work on FGM education.

How was I identified and why am I being invited to participate in this research?

You have been invited to participate in this study, through the poster campaign, because you are a woman and a community educator working in the area of FGM from Somali, Eritrean, Indonesian and Kurdish communities and you are over the age of 18. Should you choose to participate you can contact me at the email address below.

What will happen in this research?

The project involves individual interviews and one focus group discussion. The individual interview will take place at your home or a place you feel comfortable. As a participant, you will be asked to spend a maximum of one hour being individually interviewed about your stories of women living with FGM in your community. After the interview you will be asked to take part in one focus group discussion with three other women community educators. The focus group discussion will be about strategies for FGM education. This focus group will occur at a community center in a location accessible for you and the other participants. Any information you give about other people will be maintained and kept confidential.

Both the individual interview and focus group discussion will be audio taped and later transcribed.

Your participation in this research project is voluntary and you may withdraw from the study at any time prior to the completion of the interview and the focus group discussion. However, it might be difficult to delete all your data from the focus group transcripts and notes.

What are the discomforts and risks?

There is some risk of discomfort during the interview or focus group discussion given the sensitive nature of the focus of this research. However, depending on your individual situation, there is a possibility that you may feel uncomfortable or distressed talking about these issues.

How will these discomforts and risks be alleviated?

You have the choice to stop the interview and withdraw from the focus group discussion at any time. Also, at your request, referral can be made to a counsellor to discuss any concerns following the interview/focus group discussion.

Free counselling session can be arranged through the AUT Counselling Service. If you would like a counselling session please do the following:

- They will need to contact our centres at WB219 or AS104 or phone 09 921 9992 City Campus or 09 921 9998 North Shore campus to make an appointment
- They will need to let the receptionist know that they are a research participant
- They will need to provide your contact details to confirm this
- They can find out more information about our counsellors on our website:

[http://www.aut.ac.nz/students/student\\_services/health\\_counselling\\_and\\_wellbeing](http://www.aut.ac.nz/students/student_services/health_counselling_and_wellbeing)What are the benefits?

Although there are no immediate personal benefits, the opportunity to share personal views on FGM could be a useful learning experience and shared social support for those involved. The completion of this research project also means that issues relating to FGM will be disseminated.

How will my privacy be protected?

In this study both the individual interview and focus group discussion will be recorded and all the recordings will be transcribed and the materials will remain confidential. They will only be available to the researcher and research supervisor. No information identifying you as the participant in this study will be included in the thesis.

What are the costs of participating in this research?

There is no cost for you for taking part in this study. Any costs incurred travelling to the focus group venue will be covered by the study. We will also provide refreshments at the focus group in appreciation of your time.

What opportunity do I have to consider this invitation?

If you are interested in taking part you may want to contact me, Ayan Said, on the email address or phone number below to discuss the research. Participants will be selected on a first come first served basis.

How do I agree to participate in this research?

If you agree to participate in this research, you are asked to complete a consent form. This will be provided to you by myself, Ayan Said. Once the consent form has been completed I will make contact with you.

Will I receive feedback on the results of this research?

Yes, there will be an initial summary of themes in the FGD. Also, the final research report will be made available for you to read.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr Penny Neave, [pneave@aut.ac.nz](mailto:pneave@aut.ac.nz) (09) 921 9999 Ext 7769

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEK, Kate O'Connor, [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz) , 921 9999 ext 6038.

Whom do I contact for further information about this research?

Researcher Contact Details: Ayan Said [ayan.s3000@gmail.com](mailto:ayan.s3000@gmail.com) 02102289239.

Project Supervisor Contact Details: Dr Penny Neave, [pneave@aut.ac.nz](mailto:pneave@aut.ac.nz) (09) 921 9999 Ext 7769

Approved by the Auckland University of Technology Ethics Committee on type the date final ethics approval was granted, AUTEK Reference number type the reference number.

## Appendix C: Consent Form

Consent Form



Project title: Stories and strategies of women living with Female Genital Mutilation among the Somali, Eritrean, Indonesian and Kurdish communities in New Zealand.

Project Supervisor: Dr Penny Neave

Researcher: Ayan Said

- I have read and understood the information provided about this research project in the Information Sheet dated 8 April 2014.
- I have had an opportunity to ask questions and to have them answered.
- I understand that notes will be taken during the interviews/ focus group and that they will also be audio-taped and transcribed.
- I understand that during the interview/ focus group I need to maintain confidentiality when referring to other people
- I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
  - I understand that any information I give about other individuals will be in confidence
- If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- I agree to take part in this research.
- I wish to receive a copy of the report from the research (please tick one): Yes  No

Participant's signature: .....

Participant's name: .....

Participant's Contact Details (if appropriate):

.....  
.....  
.....  
.....

Date:

Approved by the Auckland University of Technology Ethics Committee on type the date on which the final approval was granted AUTEK Reference number type the AUTEK reference number

Note: The Participant should retain a copy of this form.

## Appendix D: Ethics approval



AUTEC  
SECRETARIAT

5 August 2014

Penny Neave

Faculty of Health and Environmental Sciences

Dear Penny

Re Ethics Application: 14/105 Stories and strategies of women living with Female Genital Mutilation (FGM) from the Somali, Eritrean, Indonesian and Kurdish communities in Auckland.

Thank you for providing evidence as requested, which satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC).

Your ethics application has been approved for three years until 4 August 2017.

As part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 4 August 2017;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 4 August 2017 or on completion of the project.

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply there.

To enable us to provide you with efficient service, please use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at [ethics@aut.ac.nz](mailto:ethics@aut.ac.nz).

All the very best with your research,

A handwritten signature in black ink, appearing to read 'K O'Connor'.

Kate O'Connor

Executive Secretary

Auckland University of Technology Ethics Committee

Cc: Ayan Said [ayan.s3000@gmail.com](mailto:ayan.s3000@gmail.com)