The maternity care experiences and needs of migrant women with female genital mutilation living in Australia

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Table of Contents

Certificate of Original Authorship

I declare that this thesis is submitted in fulfilment of the requirements for the award of doctoral degree, in the Faculty of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

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Dedication

This work is dedicated to my late mother, ‘Parvin’ who wished to see me at the top of the mountain of success. The woman who sacrificed her dreams for my growth and empowerment. She made me to be the person I am today and constantly motivated me to keep working toward creating the best version of myself.

My mother strongly fought with her whole tribe, traditions and culture to ensure I’d have all the potential opportunities and possibilities to be educated and empowered and achieve my dreams and goals. She taught me to be prepared and to stay strong in the face of challenges and difficulties with faith, resilience and humility. Her life is a constant source of inspiration for me.

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I am proud of myself for arriving at this day and accomplishing such an important milestone despite all the lumps and bumps in my life. All those challenges and difficulties that I have been through, pushed me toward this point of my life, as an Afghan woman attaining a higher level of education. Coming from a conservative society, where women have no basic human rights, I am honoured and humbled to be the first midwife and one of the few women from Afghanistan who hold a post-graduate research degree. The choice I made to obtain a PhD is not something to be taken for granted, there are millions of women in Afghanistan who continue to face barriers accessing basic levels of education. I am immensely grateful and uphold this honour on behalf of all Afghan women and I now have the confidence, capacity and commitment to do great things and make the situation better for those minorities.

During this journey, many people crossed my path - each inspired me with unique energy and support and each with a new lesson for me to learn. Often times I wish I was able to invite all these people into one room and present my deep gratitude to each of them individually, for their genuine support and kindness. Thank you all for your kindness and support even if I cannot count you all or remember to mention you here, I hope you all feel my love and gratitude.

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‘Embrace the struggles and let them make you stronger’

Dissemination

Peer reviewed publications

Turkmani, S., Homer, C.S.E. & Dawson, A. 2018, 'Maternity care experiences and health needs of migrant women from female genital mutilation–practicing countries in high-income contexts: A systematic review and meta-synthesis', *Birth*. 46 (1), pp.3 –14

This peer reviewed paper is included in Chapter Two of my thesis and was published during my PhD candidature. Below is the summary of contribution for each author.

Area of contribution	**Percentage of contribution**
Concept and design of the study	ST 90%, AD; CH 10%
Supervision and conduct of research	ST 80%, AD; CH 20%
Data analysis and interpretation	ST 75%, AD; CH 15%
Writing of the initial manuscript	ST 80%, AD;CH 20%
Manuscript revisions	ST 90%, AD; CH 10%

Technical publications

These background papers were also published during my PhD candidature, but they are not part of my thesis.

Turkmani, S., Homer, C., Varol, N. & Dawson, A. 2018, 'A survey of Australian midwives' knowledge, experience, and training needs in relation to female genital mutilation', *Women and Birth*, vol. 31, pp. 25-30.

Varol, N., Hall, J.J., Black, K., **Turkmani, S.** & Dawson, A. 2017, 'Evidence-based policy responses to strengthen health, community and legislative systems that care for women in Australia with female genital mutilation/ cutting', *Reproductive Health*, vol. 14, no. 1, p. 63.

Conference Presentations

1. Turkmani, S., Homer, C., Dawson, A. (2019) Hearing women's voices: a study of the maternity care experiences and needs of migrant and refugee women with female genital mutilation, *Women Deliver Conference,* June 3-6*,* Vancouver, Canada.

2. Turkmani, S., Homer, C., Dawson, A. (2019) The Maternity Care Experience of Women with FGM in Australia. *3rd International Expert meeting on Management and prevention of Female Genital Mutilation/Cutting* May 20-21, Brussels, Belgium.

3. Turkmani, S., Homer, C., Varol, N. & Dawson, A. A survey of Australian midwives' knowledge, experience, and training needs in relation to female genital mutilation. *The Australian College of Midwives 20th National Conference*, November 2017. Adelaide, Australia.

4. Turkmani, S., Homer, C., Dawson, A., Midwives' experience, knowledge and needs regarding the care of women with Female Genital Mutilation in Australia. *31st ICM Triennial Congress,* June 2017, Toronto, Canada.

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Abbreviations

ABS	Australian Bureau of Statistics
AI	Appreciative Inquiry
AIHW	Australian Institute of Health and Welfare
FGDs	Focus Group Discussions
FGM	Female Genital Mutilation
HICs	High Income Countries
HREC	Health Research Ethics Committee
NGOs	Non- Governmental Organisations
NSW	New South Wales
PTSD	Post Traumatic Stress Distress/Disorder
QMNC	Quality Maternal and Newborn Care
RA	Research Assistant
UK	United Kingdom
UN	United Nations
UNICEF	United Nations Child Fund
US	United States
UTS	University of Technology Sydney
WHO	World Health Organization

Glossary of terms

Female Genital Mutilation (FGM): Female genital mutilation (FGM) includes all procedures that involve the partial or total removal of the external genitalia or other injuries to the female genital organs (such as stitching of the labia majora or pricking of the clitoris) for non-medical reasons. World Health Organization (2016a) classified FGM in four types (I, II, III, VI) and, based on its severity, each type has its own sub-classification as explained here:

> **Type I (Clitoridectomy)**: Partial or total removal of the clitoris and/or the prepuce. **Type Ia:** removal of the prepuce/clitoral hood and **Type Ib:** removal of the clitoris with the prepuce.
>
> **Type II (Excision)**: Partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora. **Type IIa:** removal of the labia minora only, **Type IIb:** partial or total removal of the clitoris and the labia minora and **Type IIc:** partial or total removal of the clitoris, the labia minora and the labia majora.
>
> **Type III (Infibulation)**: Narrowing of the vaginal orifice with the creation of a covering seal by cutting and appositioning the labia minora and/or the labia majora, with or without excision of the clitoris. **Type IIIa:** removal and appositioning the labia minora with or without excision of the clitoris and **Type IIIb:** removal and appositioning the labia majora with or without excision of the clitoris.

Type IV: All other harmful procedures to the female genitalia such as pricking, pulling, piercing, incising, scraping and cauterization for non-medical purposes.

Infibulation: It is the equivalent term for Type III that is explained above.

Re-infibulation: The procedure of sewing to narrow the vaginal opening in a woman after she has been deinfibulated (i.e. after childbirth); also known as re-suturing.

De-infibulation: The practice of cutting open the narrowed vaginal opening in a woman who has been infibulated, which is often necessary for improving health and well-being as well as to allow intercourse or to avoid complications or facilitate childbirth.

FGM-equivalent terms used by women: ‘Khetan’, ‘Sunnat’, ‘Ferawni’, ‘Guduttan’, ‘Cut’, ‘Closed’, ‘Circumcised’, ‘Excised’.

Abstract

Background

Female genital mutilation (FGM) is a cultural practice defined as the partial or total removal of the external female genitalia for non-therapeutic reasons. Changing patterns of migration have resulted in clinicians in high-income countries caring for more women from countries where FGM is traditionally practised. Women affected by FGM who are pregnant and giving birth may require specialist care depending on their individual needs and type of FGM. However, many clinicians in these countries are unfamiliar with FGM, posing a challenge to the provision of quality of care. There is a lack of research in high-income countries that focuses on the maternity care experiences of women with FGM, that is necessary to ensure quality care.

Aim

The aim of this study was to explore the maternity care experience and needs of women affected by FGM who have migrated to Australia and to inform culturally safe and high-quality woman-centred care and contribute to maternity policy and practice improvements.

Method

Appreciative Inquiry was used as a collaborative approach to identify positive care experiences and create a participatory approach to engage women. Women with FGM were recruited through chain referral and the involvement of a community. Twenty-three semi-structured interviews and four focus group discussions (FGDs) were conducted in metropolitan Sydney. All data, including field notes, were analysed thematically using the 4Ds cycle of Appreciative Inquiry (Discovery, Dream, Design and Develop).

Results

Twenty-seven women affected by FGM from a range of countries participated in this study. The analysis revealed five major themes: (1) My FGM story, (2) appreciating the best in their experiences; (3) achieving their own dreams; (4) planning together; and (5) acting, modifying, improving and sustaining.

Subjective measures of ideal quality maternity care were identified based on women’s perceptions and expectations. Women acknowledged the reality of maternity care and situations when it was not of the quality they desired or expected. Women reported that they were not always engaged in all aspects of their care. Most women expressed their desire to play an active role in their care, but they struggled with poor communication and a lack of information tailored to their individual needs. Women identified their meaningful involvement in the design and delivery of their care as a key strategy for improving and validating the quality of the maternity services they received.

Discussion

Women with FGM in this study had a clear understanding of their health and cultural needs. It is necessary to engage women as equals in the design and delivery of their own health care services. Such a level of partnership will ensure and sustain the quality of health services by centring woman and collaborating with them to deliver health care that meets their physical, emotional and cultural needs, thereby achieving quality care for affected women.

Conclusion

This study is one of the first of its kind in Australia and provides an understanding of policy, socio-cultural and healthcare gaps, and strategies required to build self-efficacy and improve health outcomes for women with FGM. The findings from this research can be used as an advocacy tool or guideline to inform policy and practice and improve the quality of care for affected women through a participatory approach to co-designing future maternity care for women affected by FGM.

Chapter 1

Introduction

Female genital mutilation (FGM) is defined as partial or total removal of external female genitalia for non-therapeutic reasons (UN 2008). This practice is deeply rooted in culture, with social obligation and marriageability considered to be two of the most important reasons for its continuation (UNICEF 2013). FGM has also been linked with a girl's transition from childhood to womanhood (Kaplan et al. 2013; UN 2008) and is perceived as a religious requirement, understood to maintain the family honor. FGM is also performed for aesthetic reasons, and for fear of being excluded from resources and opportunities as a young woman (UNICEF 2010). FGM is traditionally practised in 30 African and Middle Eastern countries, and in some parts of Asia and South America (UNICEF 2015) and Russia (The Guardian 2016).

Overall, the prevalence of FGM is declining globally, and the proportion of girls being cut is less compared with the previous generation (UNICEF 2013). However, with increasing population growth, the total number of girls subjected to this practice is still likely to grow (UNICEF 2014, 2015). It is estimated that 200 million women and girls have undergone FGM worldwide and another three million are at risk annually (UNICEF 2015; WHO 2016a). Over the last three decades, many FGM prevention strategies, such as, the training of health professionals, mass media campaigns, community mobilisation and law enforcement, have been implemented, some of which have been found to have minimal or no contribution to the reduction of this practice (Berg & Denison 2012; Diop & Askew 2009; Waigwa et al. 2018). However, evidence on the long-term effect of such interventions and its impact on the prevention of FGM is limited and all is focused on the African context (Johansen et al. 2013; Njue et al. 2019). (Figure

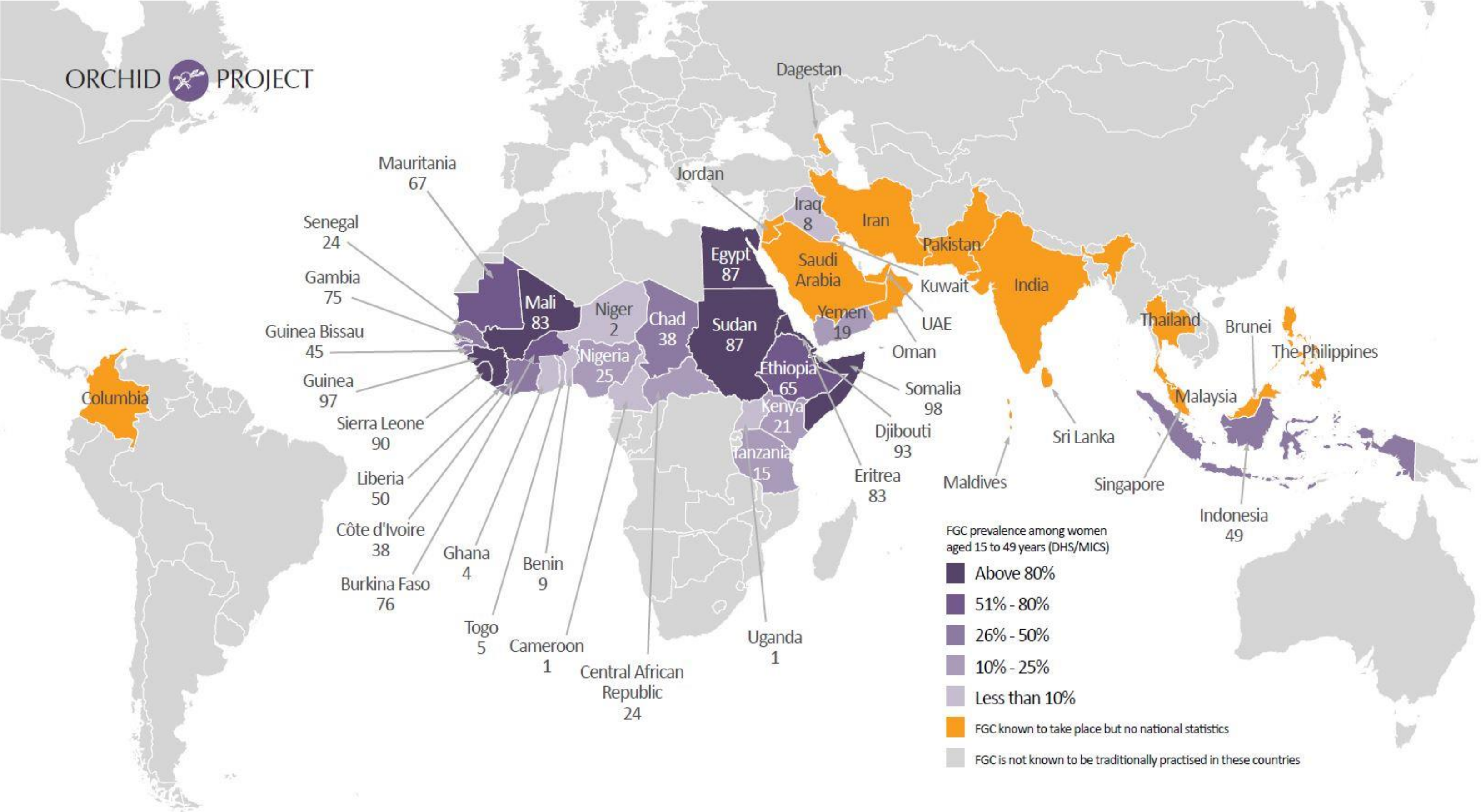


Figure 1: Global Map of FGM (Orchid_Project 2018) https://www.orchidproject.org/wp-content/uploads/2019/04/World-map prevalence_Orchid_Project_2018.pd

Many high-income countries (HIC) with immigrant populations have seen an increase in the number of women with FGM (UN 2008; UNICEF 2015; WHO 2016a). As a consequence, healthcare professionals in high-income countries are increasingly caring for women with FGM who now live across Europe, the United States (US), the United Kingdom (UK), Australia, New Zealand and Canada (Abdulcadir et al. 2011; Korfker et al. 2012; Stockdale & Fyle 2012; Yoder & Khan 2008). Despite this understanding, there is a lack of reliable and high-quality data in relation to the numbers of women affected by FGM in HICs (Blignault & Haghshenas 2005). Inadequate reliable sources of data on the prevalence of FGM makes it challenging for countries to develop effective policies, allocate relevant resources and evaluate the results of interventions (European Institute for Gender Equality 2013; Teixeira & Lisboa 2016; Ziyada, Norberg-Schulz & Johansen 2016). Some HICs have estimated the number of women and girls with FGM using modelling based on prevalence in countries of migration to direct their policies and practice. Using this approach, in 2011, it was estimated that in the UK there were 103,000 women in the age range of 15-45 years living with FGM. This denotes an estimated prevalence of 7.7 (Macfarlane & Dorkenoo 2015). In Norway, 44,467 of immigrant women were born in countries where FGM is traditionally practiced And it has been estimated that approximately 40 percent of these women have been subjected to FGM (Ziyada, Norberg-Schulz & Johansen 2016). A recent report by the Australian Institute of Health and Welfare (2019b) estimated that in 2017 there were 53,000 women and girls affected by FGM in Australia, which represents a prevalence of 4 per 1000 girls and women in Australia.

Most women affected by FGM are from refugee and migrant backgrounds and more likely to face socio-economic and cultural challenges because of language barriers, low education levels, and financial difficulties, which hinders access to health services

(Burnett & Ndovi 2018; Varol et al. 2017). Many of these women have suffered prior physical and mental health issues as a result of being exposed to torture and trauma, such as rape and sexual violence, and they are also more likely to experience stigma and isolation due to lack of social support (Asgary & Segar 2011). Many women may also lack an awareness of their rights and status in their host country (WHO 2018b) and a large number of these women are reluctant to seek or receive medical help (Schubert & Punamäki 2011). Migrant and refugee women from low and middle-income countries, especially those from African countries, are reported to have poorer perinatal outcomes due to a higher rate of complications during pregnancy and childbirth (Belihu, Davey & Small 2016; Gibson-Helm et al. 2014).

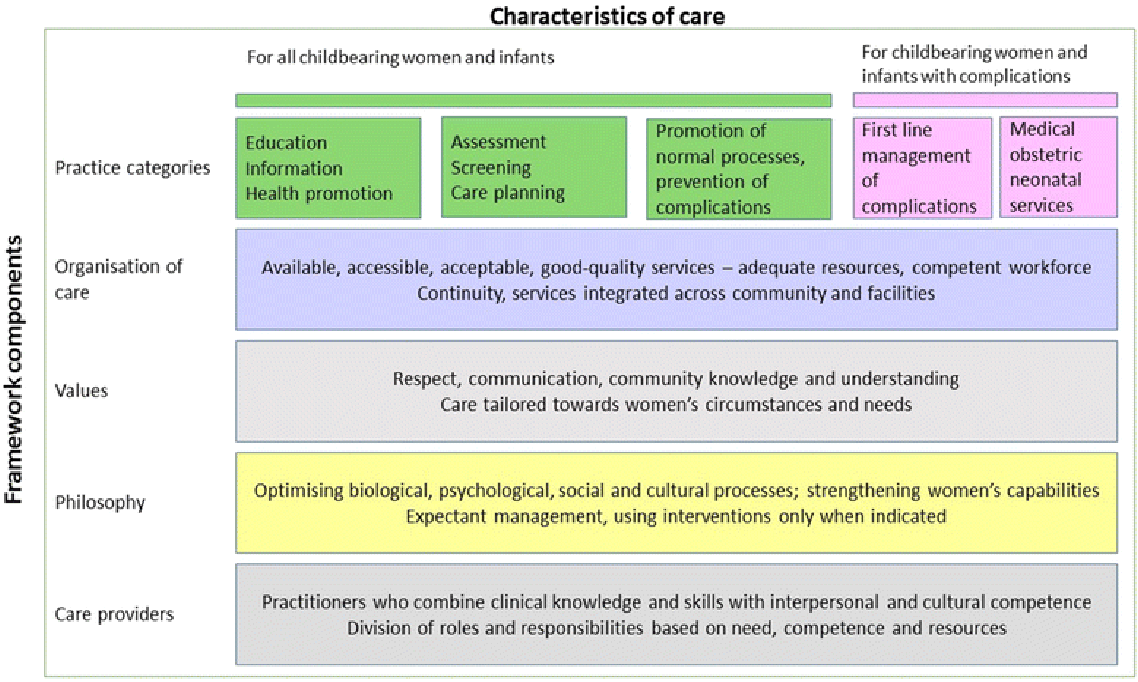
FGM poses an additional burden to affected women and there can be serious and often adverse consequences during pregnancy and childbirth such as the increased risk of caesarean section, post-partum haemorrhage, instrumental delivery, prolonged labour (WHO 2016a). This also includes immediate and lifetime physical and psychosexual health problems, such as urinary tract infections and renal insufficiency, chronic pelvic and vulvar pain, dysmenorrhoea, menstrual problems and sexual complications (Almroth et al. 2005; Elnashar & Abdelhady 2007; Talle 2007). A World Health Organization (WHO) multi-centre study among African women from six countries showed that women with FGM have a higher risk of poor outcomes such as fetal distress and stillbirth than women without FGM (WHO 2006a). Women with FGM in some HICs have also been found to delay seeking care or refuse medical interventions such as emergency caesarean section. This could be due to lack of health providers' cultural behaviour awareness and ineffective communication between women and care providers (Essen et al. 2002; Vangen et al. 2002).

Research has found that health services in some HICs may not be adequately prepared to provide quality care to women affected by FGM. For example, many health professionals are unfamiliar with the practice of FGM, lack the clinical skills that may be required to care for women during pregnancy and/or labour and have inadequate knowledge about the law in relation to FGM (Dawson, Homer, et al. 2015; Dawson, Turkmani, Varol, et al. 2015; Leye et al. 2008). These issues, combined with the lack of support services, such as interpreting and counselling services (Turkmani et al. 2018) adds other challenges. In many HICs, any female genital repair after birth with the aim of re-suturing the vaginal opening which is known as re-infibulation (WHO 2016a) is illegal. However, there have been reports of such activities after birth in Sweden, Australia and Norway (Lundberg & Gerezgiher 2008; Moeed & Grover 2012; Vangen et al. 2004). Women affected by FGM in HICs are usually migrants from culturally diverse backgrounds and may have complex or different needs that go beyond clinical care while incorporating the concepts of women's rights and cultural values (Hulton, Matthews & Stones 2000; Van den Broek & Graham 2009).

The report of 'Migrant and Refugee Women's Health Partnership' (2017) highlighted the significance of cultural competence and emphasised the importance of health professionals' understanding the effect of culture on health while providing safe, respectful and high quality care to those marginalised and vulnerable among the population. Importantly, culturally sensitive care where appropriate information is provided or timely empathetic referral occurs is likely to improve outcomes (Milosevic, Cheng & Smith 2012). However, health professionals report lacking an understanding of the cultural background of women affected by FGM and that communication can be challenging (Dawson, Turkmani, Varol, et al. 2015). Additionally, the difficulties women face expressing their needs and concerns pose additional challenges in providing quality of care in the context of maternal health (Hoang, Le & Kilpatrick 2009; Ogunsiji 2015; Pranee C. Lundberg 2008; Relph et al. 2013; Rogers & Earnest 2013). FGM is considered a culturally sensitive topic and not openly discussed within communities (Connelly et al. 2018; Dixon et al. 2018).

The provision of a culturally safe, quality care for mothers and babies is the goal for any health system and it has been articulated in a number of ways in recent years. WHO (2006b) has defined quality care according to a series of standards that services should meet. These emphasise the effective, efficient, accessible, acceptable and safe care with consideration of a women's individual needs (WHO 2016a). Recently, the framework for Quality Maternal and Newborn Care (QMNC) developed by Renfrew et al (2014), highlights the essential characteristics of woman-centred quality care (Figure 2). The QMNC framework has a number of key platforms necessary for quality care including specific clinical and educational practices, the organisation of care, attention to the values and philosophy of care and the importance of skilled and compassionate care providers. The central focus of this framework is the provision of appropriate individualised services that are respectful and culturally sensitive. However, the QMNC framework was considered as a generic tool that can serve to explore women's generic needs during maternity. However, the QMNC is not designed for specific populations of women, such as those affected by FGM.

Figure 2: QMNC framework
https://www.sciencedirect.com/science/article/pii/S0140673614607893?via%3Dihub



WHO highlights the importance of the provision of quality health care for women who are affected by FGM in order to minimise further complications and harm (WHO 2016a). While there are some insights into what constitutes quality maternal care from the perspective of the health system, a gap remains concerning the views of women with FGM. This doctoral research sought to address the current knowledge gaps in maternity care from the perspective of migrant women in Australia who have experienced FGM.

This study engaged women affected by FGM to share their experiences as an important step to identify the best approaches to inform culturally safe and high-quality woman-centred care. These research findings will contribute to improving maternity care by involving women themselves in the process of maternity service design. In the next sections, the aim, research questions and background to this PhD study are discussed.

Aim

The aim of this study was to explore the maternity care experience and needs of women affected by FGM who have migrated to Australia and to inform culturally safe and high-quality woman-centred care and contribute to maternity policy and practice improvements.

Research questions

There were six research questions. These were:

1. What do women affected by FGM perceive as quality maternity care?
2. How do women with FGM feel that their culture is acknowledged by maternity care services and how could this be improved from the perspective of cultural safety?
3. How do the relationships that women affected by FGM have with obstetricians, midwives and other health professionals during pregnancy and after birth impact on quality care?
4. How have women with FGM experienced maternity care decision-making and how do women think decision-making could be improved?
5. What expectations do women with FGM have of maternity health services in Australia and were they satisfied with the care they received?
6. How can women with FGM be more involved in the co-production of maternity care, services and information?

Background and context

Australia has become home to a growing population of women from FGM-practising countries due to global migration and humanitarian crises. As no national prevalence data is collected, it is difficult to estimate the number of pregnant women with FGM in Australia. In the most populous state of New South Wales (NSW) in 2017, almost 40% of women giving birth each year were born overseas and 38% of women using maternity services were non-English speaking. Of these women, 5.3% were born in the Middle East or Africa, which are the primary locations for the practice of FGM (Centre for Epidemiology and Evidence 2017), suggesting that there are increasing numbers of FGM affected women in NSW.

There has been an increase in the number of women and girls who have migrated from FGM practising countries to Australia from about 67,000 to 164,500 who may have undergone FGM between 1998 and 2017 (Australian Institute of Health and Welfare 2019a). In 2017, it was estimated that approximately 0.4% of women and girls in Australia might be living with FGM, in which 57% are at childbearing age (Australian Institute of Health and Welfare 2019b). At a local level, data from the medical records at one maternity hospital in Sydney indicated an increase in the prevalence of pregnant and childbearing women with FGM from 1.8% to 2.8% between 2006 and 2012 (Varol et al. 2016).

For more than 20 years, Australia, like many other countries, has recognised FGM as a violation of human rights. In 1994, NSW was the first Australian state to make FGM illegal and subsequently, all the other states and territories endorsed legislation against FGM (Commonwealth Attorney-General 2013). In NSW, according to the latest version of the ‘Crimes Amendment Bill (FGM Bill 2014) Act No. 40 [NSW]’, arranging, performing or attempting to perform any type of FGM including clitoridectomy, excision of any other part of the genitalia, infibulation, and any other mutilation of the genitalia is illegal. Penalties include 7 to 21 years of imprisonment ('Crimes Amendment (Female Genital Mutilation) Bill 2014 [NSW]'). These laws, alongside the health implications of FGM, were highlighted in a review of the national FGM Framework by the Commonwealth Government in 2013 (Commonwealth Attorney-General 2013). This national FGM framework provided recommendations and a commitment to continue working with states and territories to address gaps mainly in relation to the legal aspects. The main emphasis of national agenda was on the need for collaboration between the health system, communities and legal system for knowledge and data sharing to protect vulnerable women and children in Australia.

The implementation of legislation in Australia, paired with community education interventions and resources, aims to address the needs of affected communities (Chen & Quiazon 2014a). ‘The National Education Toolkit for FGM/C Awareness (NETFA)’ aimed to educate affected communities across Australia (Chen & Quiazon 2014a). In 1997, the NSW FGM education program initiated state-wide activities with a focus on mobilising and training women and men in the community to prevent the practice and improve the reporting system through linkages with the community (NSW FGM 2014). However, there remains a lack of community and health care providers’ knowledge concerning the legal aspects of FGM. Some health care providers in Australia have reported that they have seen children with FGM or have been asked by their patients to perform re-infibulation and have performed FGM (Moeed & Grover 2012; Sureshkumar et al. 2016; Zurynski et al. 2015). There have also been media reports of cases, either before the courts or under investigation, where parents have sought to have FGM performed on their girl children in NSW, Queensland and Victoria (Hall 2014; Jabour 2015; Margetts 2016; Vujkovic 2018). In 2019, the media reported the conviction of a woman for arranging for her two daughters to have FGM performed in Somalia (Barnsley 2019).

Most public hospitals in Victoria and NSW that provide reproductive and maternity services have developed their own guidelines for clinical practice and referral pathways (Chen & Quiazon 2014a). However, the provision of specialised FGM services, such as, counselling and psychological support in the communities where affected women reside are required to ensure standardised care (Turkmani et al. 2018; Varol et al. 2017). Studies also show that the implementation of such guidelines and policies in clinical settings is not always effectively communicated with health care providers (Turkmani et al. 2018; Varol et al. 2017). Professional associations are also providing advice and online resources for care providers with an emphasis on health providers' own responsibility to follow, manage or refer women with FGM (ACM 2013; RANZCOG 2015). However, professional education is not coordinated, available or promoted at the national level. In addition, the lack of documentation and evaluation of prevention interventions make it challenging to identify and scale up best practices among affected communities who have settled in Australia (Chen & Quiazon 2014a; Chen & Quiazon 2014b).

The Australian public health system provides universal access to maternity health care services to migrant and refugee women after resettlement in Australia (Department of Human Services 2019). However, evidence indicates these women face difficulties navigating an unfamiliar health system and due to language barriers, low health literacy and complex social needs, the health system may not be able to respond to their specific needs (Riggs et al. 2012; Yelland et al. 2014). There is also evidence that migrant women who are affected by FGM experience racial and cultural disrespect or physical disrespect or abuse during pregnancy and childbirth (Carolan 2010). These women might feel stigmatised and embarrassed or ashamed to discuss and talk openly about their concerns due to cultural differences, traditional beliefs and language barriers (Chalmers & Hashi 2002; Victorian Refugee Health Network 2012). Cultural barriers may lead to a lack of understanding of the needs of this group of women, which can affect the quality of care they receive (Hoang, Le & Kilpatrick 2009). The cultural competency of health providers is an important dimension of quality care but women often report feeling culturally unsafe (Hoang, Le & Kilpatrick 2009; Small et al. 2014). The way care is provided and the skills and capabilities of the health workforce are critical in the provision of quality care (Renfrew et al. 2014).

There are a small number of studies in Australia that have explored the knowledge and experiences of providers such as midwives, paediatricians and obstetricians (Dawson, Turkmani, Varol, et al. 2015; Moeed & Grover 2012; Ogunsiji 2015; Sureshkumar et al. 2016). These studies have indicated major gaps in the technical knowledge and skills of providers and a general lack of awareness about the laws and guidelines surrounding FGM (Dawson, Turkmani, Varol, et al. 2015; Ogunsiji 2015; Turkmani et al. 2018). The Australian evidence also highlights the need for ongoing education of health care professionals and advocacy for the abandonment of this harmful practice (Dawson, Turkmani, Fray, et al. 2015; Turkmani et al. 2018; Varol et al. 2017).

Research has identified the need for expertise and an understanding of the issues related to FGM to inform maternity health service planning and delivery (Dawson, Turkmani, Varol, et al. 2015). Services need to shift focus towards the experiences of receivers of health care in service design rather than the traditional approach of focusing on the ability of health professionals and health care system to deliver high-quality care (Dagger 2007). The importance of understanding women's views on the quality of care they are receiving will provide practical strategies for strengthening health services. The focus of this study, therefore, is to provide evidence from the perspective of women with FGM and explore their experiences and needs in relation to quality maternity care in Australia.

Significance of the study

Research with vulnerable or specific groups of women (Bhanot 2007; Boerleider et al. 2014), such as those who have undergone FGM, is important (Kaiev 2004). Firstly, the demography of the world's population is constantly changing due to migration (IOM 2013) and, as a result, public health issues such as FGM are global concerns and not just those of high prevalence countries (UNICEF 2015; WHO 2016a).

Secondly, the voices of women affected with FGM are often missing across the literature and the existing evidence mainly reflects the voice of health providers and concerns about the health system itself. Studies previously undertaken in Australia have also shown that further research on needs of women affected by FGM due to cultural issues, communication barriers and low flexibility of health providers to improve their cultural awareness and provide culturally competent services to a diverse population is necessary (Dawson, Turkmani, Varol, et al. 2015; Varol et al. 2016). The engagement of specific groups of women to enable them to participate in health improvement processes may enable them to express their needs and increase their sense of responsibility over their own health and promote the health of society (Turkmani, Homer & Dawson 2018).

Research in this area can provide knowledge concerning the design of maternity care that ensures that the needs of a growing diverse population is addressed by the health system. This unique study sought to understand how maternity care can be improved by an understanding of the experiences and expectations of women who have received such care as well as their cultural values and practices. The recommendations of this research may address the barriers to maternity care thereby improving access to health services and resources. The findings can be used to develop advocacy tools or to inform guidelines, policy and practice concerning care for women affected by FGM. These strategies might also be beneficial for other contexts with similar populations.

Thesis Outline

This thesis is organised in nine chapters. Below is a brief description of each chapter:

Chapter one is an introductory chapter providing an outline of the background, aim, research questions and rationale for the study. This chapter also highlights the Australian context for women who have undergone FGM and live in Australia and briefly describes the existing laws in relation to FGM in Australia.

Chapter two presents a systematic review of global literature exploring maternity care experiences and needs of migrant women who have undergone FGM and live in HICs. This review identifies significant gaps between what is known as aspects of quality health care and what migrant women who have undergone FGM perceive or experience as quality care that fulfils their health needs. This chapter was published in 2018 as part of this PhD project (Turkmani, Homer & Dawson 2018).

Chapter three describes the methodology and methods used in this study and their justification. A social constructivist approach was used as the philosophical stance, combined with theoretical perspectives of interpretivist and critical theory. This study constructed and integrated ideas and perceptions of women and I, as a researcher, built up my own structure and interpretation, based on existing theories and relevant research.

This chapter also elaborates Appreciative Inquiry and its 4Ds as a qualitative method that was employed in this study along with reference to the data collection and data analysis techniques.

At the end of chapter nine, I provided my own reflections and conclude the thesis, describing the implications for practice and future research.

Chapters four to eight inclusively presents the findings of this study in line with the '4Ds' cycle of Appreciative Inquiry. The findings include five key themes: 'My FGM story', 'Appreciating the positives in their maternity care (Discovering)', 'Desiring the best in maternity services (Dreaming)', 'Planning together for improved maternity services (Designing)', 'Improving and sustaining (Developing/Deploying)' Each of these themes and sub-themes are presented in these chapters.

Chapter nine is the discussion chapter that draws together the findings of the study, synthesises these with reference to the broader literature and includes my own interpretations.

Summary

This chapter has provided an overview of the cultural practice of FGM and its relation to quality maternity care. The challenges for health providers caring for migrant women in high resource settings including Australia have been described. This chapter identified the aim, research questions and the significance of the research study. The next chapter presents the literature review that explores the experience of migrant women with FGM receiving health services in nine HICs and their perception and understanding of their socio-cultural and health needs.

Chapter 2: A Systematic Review and Meta-synthesis

Introduction

This literature review synthesised the global evidence in relation to maternity and health care needs of women affected with FGM in high-income countries. The study aimed to provide insight into the maternity experiences of women. However, the review also sought to identify the gaps in health care services and what migrant women who have undergone FGM perceive to be or have experienced as quality care that fulfils their health needs.

This chapter presents the accepted version of the published paper (Turkmani, Homer & Dawson 2018) and there might be some repetition of material already provided in the background (Chapter One). The tables and figures are numbered according to the published version of the article.

Turkmani, S., Homer, C.S.E. & Dawson, A. 2018, 'Maternity care experiences and health needs of migrant women from female genital mutilation–practising countries in high-income contexts: A systematic review and meta-synthesis', *Birth*. 46 (1), pp. 3 – 14.

Background

Female genital mutilation (FGM) is defined as partial or total removal of external female genitalia for non-therapeutic indications (UN 2008). This practice is deeply rooted in culture, with social obligation, rites of passage, marriageability, the maintenance of marital fidelity and aesthetics are considered the primary reasons for its continuation (Kaplan et al. 2013; UN 2008). The practice is known to have significant detrimental impact on women's health throughout their lifetime and in relation to childbearing is associated with a higher rate of obstetric intervention and complications during labour and birth (Elnashar & Abdelhady 2007; Varol et al. 2016). For instance, a 2006 study of women from six African countries who had experienced FGM showed that women with FGM type III or infibulation, had a 30 % higher caesarean section, 70% increase in postpartum haemorrhage and a 55% higher perinatal mortality rate. (Banks et al. 2006).

FGM is practiced in 29 countries in Africa and the Middle East, as well as some Asian countries (UN 2008; UNICEF 2014). Globally, the prevalence of FGM is declining and the proportion of girls being cut is less than those from their mothers' generation(UNICEF 2013). However, increasing population growth and migration means that the total number of girls subjected to this practice is likely to grow, including in high income countries (UN 2008; UNICEF 2015; WHO 2016a).

The World Health Organization (WHO) definition of quality care for women with FGM is characterised by the need for effective, efficient, accessible, and safe care with an emphasis on continuity of care (WHO 2016a). However, delivering quality care requires knowledge of patients' needs and their context (Institute of Medicine 2001). Culturally appropriate health services and woman-centred care have been identified as core elements of quality maternity care (WHO 2016b) especially for immigrants who may be at a higher risk of serious complications during pregnancy (Almeida et al. 2013).

Studies show that health providers in high income countries are inadequately prepared to provide quality care to women who have undergone FGM as they are unfamiliar with the law in relation to FGM or with the interventions that may be required, such as de-infibulation (a procedure to open up a closed vagina or type 3 FGM) (Dawson, Turkmani, Varol, et al. 2015; Leye et al. 2008). Female genital surgery (re-infibulation) after birth with the aim of re-suturing the vaginal opening (WHO 2016a) is illegal in many high-income countries. However, there have been reports of re-infibulation after birth in such countries (Lundberg & Gerezgiher 2008; Moeed & Grover 2012; Vangen et al. 2004). The needs and concerns of women with FGM receiving maternity care have not been synthesised to inform the care received. This lack of knowledge makes it challenging for the health system as a whole, as well as individual health care providers, to respond appropriately to women's needs (Hoang, Le & Kilpatrick 2009; Ogunsiji 2015; Relph et al. 2013).

We undertook a meta-synthesis of the qualitative evidence to explore the maternity care experiences and needs of migrant women with FGM in high-income countries. We sought to identify the gap between what is known as aspects of quality health care and what migrant women who have undergone FGM perceive or experience as quality care that fulfils their health needs.

Methods

A meta-synthesis of qualitative studies was undertaken to provide an explanation of concepts and ideas across different high-income contexts to identify service gaps and provide evidence to support future maternity health service planning and models of care (Tong et al. 2012) for women with FGM.

Papers were included if they were peer-reviewed, in English, published between 2000-2016 (to ensure the relevancy of findings to current health systems), and focused on the maternity care experiences of women who have undergone FGM and migrated from high prevalence FGM countries(UNICEF 2015) to high-income countries (World Bank 2018).

An online search was conducted between June and August 2016 using the electronic databases PubMed, CINAHL, Medline, Scopus, Academic Search Complete, Science Direct, Web of Science, ProQuest Nursing and Allied Health Source, ProQuest Health and Medical Complete. In addition, hand and snowballing searches were undertaken involving an examination of the reference lists of articles reviewed to find other potentially relevant articles.

Original terms from the review questions and objectives were used to identify the search terms, as well as using the MeSH terms. In addition, we explored a variety of combinations of potential terms identified within the relevant literature. (Table 1).

Table 1: Search Terms Used in the Meta-synthesis

'Experience'	'Maternity care'	'Female Genital Mutilation'	'High Income Countries'	'Migrant Wom?n'
Opinions Views Perspectives Perceptions experience Mental Psycho-social Wom?n centred Patient centred	Matern* Midwifery Prenatal Antenatal Postnatal Obstetrics Postpartum Perinatal Reproductive Health	FGM FGM/C FGC Female Circumcision Female Cutting Female Genital Cutting	Developed countr*, (US*, America, United States, UK, United Kingdom, England, Australia Europe* Belgium Norway Holland, Switzerland, Sweden, Netherland,…)	Africa* Somal* Sudan* Middle East Wom?n Immigrant* wom?n Refugee wom?n Asylum seeker* wom?n

In the initial search, 1265 papers were identified. After the removal of duplicates, 612 remaining papers' titles and abstracts were screened for relevance. Initially, 205 relevant studies were identified, and their full text was assessed for eligibility (Table 2).

Table 2: Papers retrieved in the database Search

Data Source	Initial Search Outcome	Relevant Papers
Medline	20	11
Pubmed	24	13
Web of Science	43	17
ProQuest Health and Medicine	309	41
ProQuest Nursing and Allied Health	110	25
Scopus	316	35
Science Direct	179	23
Academic Search Complete (EBSCO)	57	21
CINAHL	4	3
Hand searched	203	16
Total	1265	205

In total, 22 papers were appraised using the critical appraisal skills program (CASP) systematic review checklist(CASP 2017) (Supplementary table 1) Of the 22 articles appraised, six papers(Andro, Cambois & Lesclingand 2014; Chalmers & Hashi 2000; Connor et al. 2016; Gele et al. 2012; Norman et al. 2009; Pavlish, Noor & Brandt 2010) were excluded as they did not adequately address the quality criteria due to methodological limitations, relevance of results, or inadequate logical connection between results and conclusions. The three authors discussed and agreed upon the final selected papers (Figure1 and Table 3).

Table 3: Characteristics of the Studies Included in the Meta-synthesis

Author/ Context	**Methodology**	**Participants**	**Aim**	**Major Finding**
Ameresekere (2011)/ USA	Qualitative- semi structured interviews	23 Somali women	To explore perceptions of caesarean delivery and patient–provider communication	Women feared postoperative complications that may result from caesarean delivery and their effect on daily life and the reactions of peers. Women felt that labour was rushed by physicians. Communication with providers was reported to be poor and providers infrequently discussed FGM, or explained its effect on childbirth experiences.
Berggren (2006)/ Sweden	Qualitative- in-depth interviews	22 women from Somalia, Sudan, & Eritrea.	To explore women's experiences of encounters with Swedish maternal health care.	Women with FGM reported feeling different and vulnerable. They felt that they were looked down on by health care personnel because they had undergone FGM.
Carolan (2010)/ Australia	Qualitative in-depth interviews	18 pregnant women (Sudan, Ethiopia, Eritrea, Somalia, Kenya)	To explore the experiences and concerns of an African-born sample of pregnant women receiving antenatal care.	African women undergo a process of adjustment as they travel from a view of pregnancy in their country of origin as not 'special' to valuing continuous antenatal care and other supportive services offered to them in Australia.

Chalmers (2002)/ Canada	Qualitative descriptive survey interviews & focus group discussions	432 Somali women	To explore recent perinatal experiences of Somali women in Canada.	Women perceived their maternity care to be disrespectful, harsh and offensive to their cultural values. Women considered their care to be inappropriate and rarely discussed birth practices and care management with their providers.
Degni (2013)/ Finland	Qualitative focus group discussions	70 Somali women	To explore immigrant Somali women's experiences and perceptions about reproductive and maternity health care services and service providers' cultural and communication competencies.	Participants were satisfied with the reproductive and maternity health care services they received. However, they perceived health care providers' communication to be poor and their attitudes unfriendly.
d'Entremont (2014)/ France	Qualitative (hermeneutic phenomenological) interviews	4 women (country not identified)	To understand the maternity needs of women with FGM.	Despite receiving regular and early antenatal care, women reported that FGM was not discussed. Women emphasized the need for midwives to communicate with them, to break the taboo of silence, and to talk openly about FGM in a respectful manner.
Essén (2000)/ Sweden	Qualitative in-depth interviews	15 Somali women	To understand how cultural factors affect perinatal outcomes and explore women's pregnancy related attitudes and behaviours.	Fear of death and caesarean section forced many women to decrease their food intake to diminish the growth of the foetus, thereby avoiding caesarean section and mortality.
Essén (2011)/ England	Qualitative (naturalistic inquiry) in-depth interviews &	39 Somali women	To explore the attitudes, perceptions and experiences of women in relation to caesarean delivery and address the relationship between Somali	Women believed there to be a strong association between caesarean birth and maternal death. Therefore they make what they perceive to be rational choices to avoid caesarean birth.

	focus group discussions		women and their western obstetric care providers.	
Bulman (2002)/ UK	Qualitative descriptive semi-structured interviews & focus group discussions	12 Somali women	To understand the views and experiences of Somali women in their contacts with the maternity services in the UK.	Poor management of FGM during childbirth, and communication and language difficulties were found to be the most important issues for women. These had negative implications for all aspects of their care.
Hill (2012)/ USA	Qualitative (phenomenology) focus group discussions	18 Somali women	To explore women's health care experiences and beliefs regarding pregnancy and birth.	Women were faced with new experiences and information. They interpreted, and reacted to this information by integrating it within their own cultural, religious, and scientific beliefs.
Lundberg (2008)/ Sweden	Qualitative (ethnographic approach) semi-structured interviews	15 Eritrean women	To explore women's experiences of FGM during pregnancy, childbirth and the postpartum period.	Most women experienced complications during pregnancy, childbirth and in the postpartum period. Women stated that knowledgeable and well-trained providers would improve the management of FGM during childbirth and reduce their risk of complications.
Moxey (2016)/ UK	Qualitative (exploratory) in-depth interviews	10 Somali women	To explore women's experience and perceptions of antenatal and intrapartum care, de-infibulation, caesarean section and vaginal delivery and factors that affect access to these services.	Women delayed de-infibulation until labour to avoid undergoing multiple operations if an episiotomy was anticipated. They reported that midwives were aware of FGM that led to open communication and stronger relationships, resulting in more positive experiences.

Murray (2010)/ Australia	Qualitative (phenomenology) semi structured interviews	10 African refugees (2 Sudanese, 2 Ethiopian, 2 Somali, 1 Liberian)	To explore the birth experiences of African refugee women in Brisbane/Australia.	Participants experienced an overwhelming sense of fear loneliness and unfamiliarity as often they had no prior contact with the Australian health system. Women often were surprised that midwives did not appear experienced in managing FGM were frustrated with lack of continuity of care.
Straus (2009)/ UK	Qualitative (ethnographic approach)	8 Somali women	To explore perceptions and experiences of childbirth.	Existing pressures as a consequence of migration were compounded by Somali women's experiences of childbirth. Inadequate care was reportedly provided during pregnancy and labour. The importance of Somalia's oral culture was not recognised when addressing communication barriers, Women reported a lack of continuity of care and felt that midwives held stereotyped and negative attitudes towards them.
Upvall (2009)/ USA	Qualitative- focus group discussions	23 Somali women	To explore health care experiences.	Circumcision is considered a normal part of everyday life. Communication and language barriers were considered obstacles to receiving care as they limit women's ability to ask health related questions.
Vangen (2004)/ Norway	Qualitative in-depth interviews	23 Somali women	To explore how perinatal care practice may influence labour outcomes among circumcised women.	Somali women felt disempowered. Women feared caesarean birth and lack of providers' knowledge on FGM.

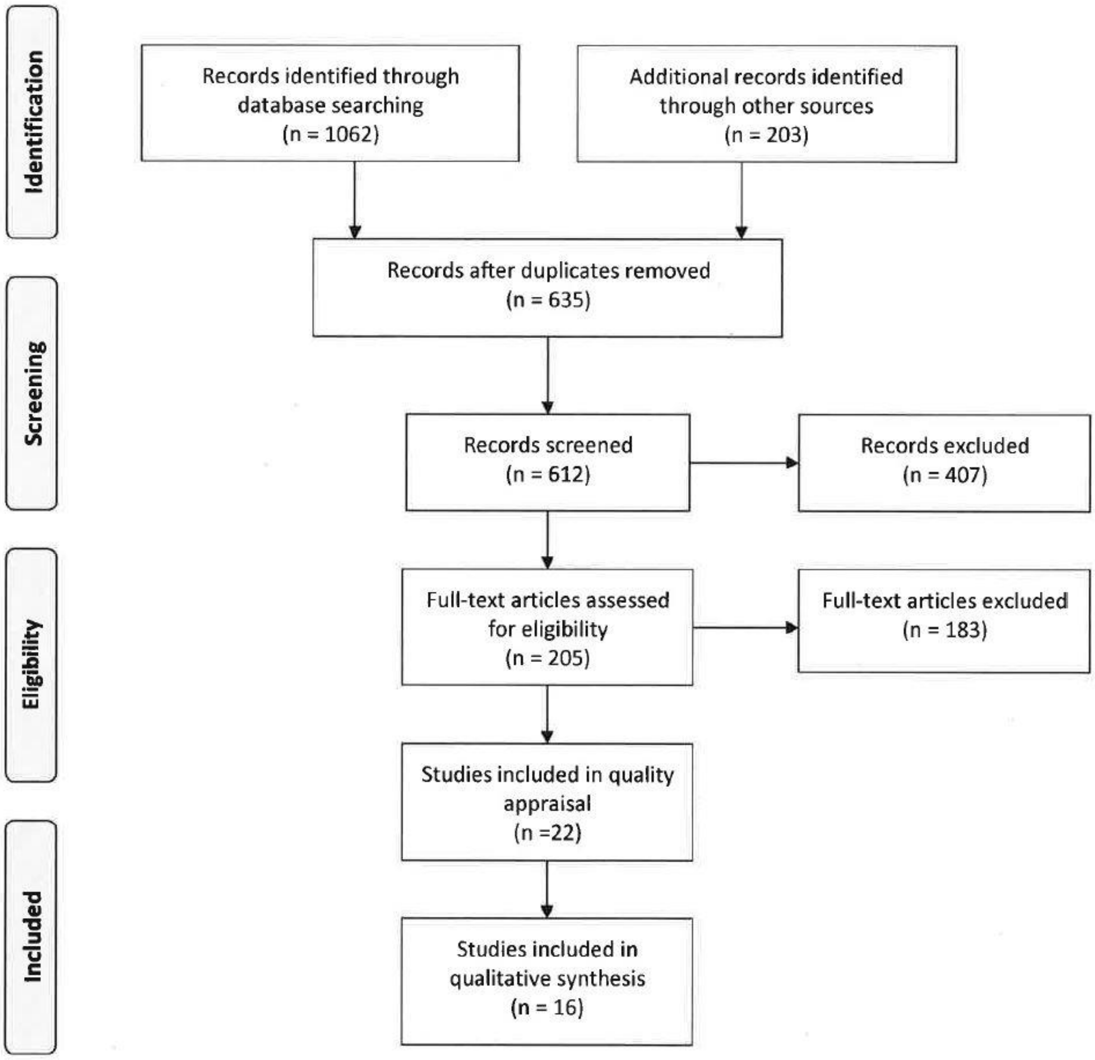


Figure 1: Search and Study Selection

The analysis was undertaken by extracting all quotations from women participants from the ‘Results’ and ‘Discussion’ sections in each paper (Tong et al. 2015). Data were imported into NVivo software to facilitate the thematic analysis by classification, coding and categorising of qualitative data as undertaken in previous meta-syntheses.(Norhayati, Surianti & Nik Hazlina 2015; Thomas & Harden 2008)

We followed Thomas and Harden’s(2008) recommended three steps for the thematic data synthesis: ‘1) Free line-by-line coding of the original quotations, 2) Grouping of similar concepts into descriptive themes, 3) Generating analytical themes that emerge from, and step beyond, the descriptive themes'.

The line-by-line coding focused on identifying the content and meaning of women's maternity care experiences. For example, sentences were coded as non-verbal disrespect if they included references such as 'dirty look', 'shocked', 'scared', 'surprised'. Patterns across the codes were then identified and codes grouped into categories. Finally, major themes and subthemes were discussed until consensus was reached among the authors. The synthesised(Britten et al. 2002) data was presented in a visual 'mind map' (Figure 2) to provide deeper insight and a more coherent understanding of the health experiences and needs of women who have undergone FGM and migrated to a high-income country.

Results

Sixteen peer-reviewed studies conducted in nine countries (four in United Kingdom, three in United States, two in Sweden, two in Australia and one each from Canada, Switzerland, Finland, France and Norway) were included. Most papers (n=11) focused on the experiences of Somali women and the remaining studies (n=5) had a mixed African study population including women from Ethiopia, Eritrea, Sudan, Kenya, Liberia and Somalia (Table 3). All studies were qualitative except for one descriptive survey(Chalmers & Hashi 2002) from which the qualitative data from the open questions were selected for this review.

Four themes were identified and are described below (Figure 2).

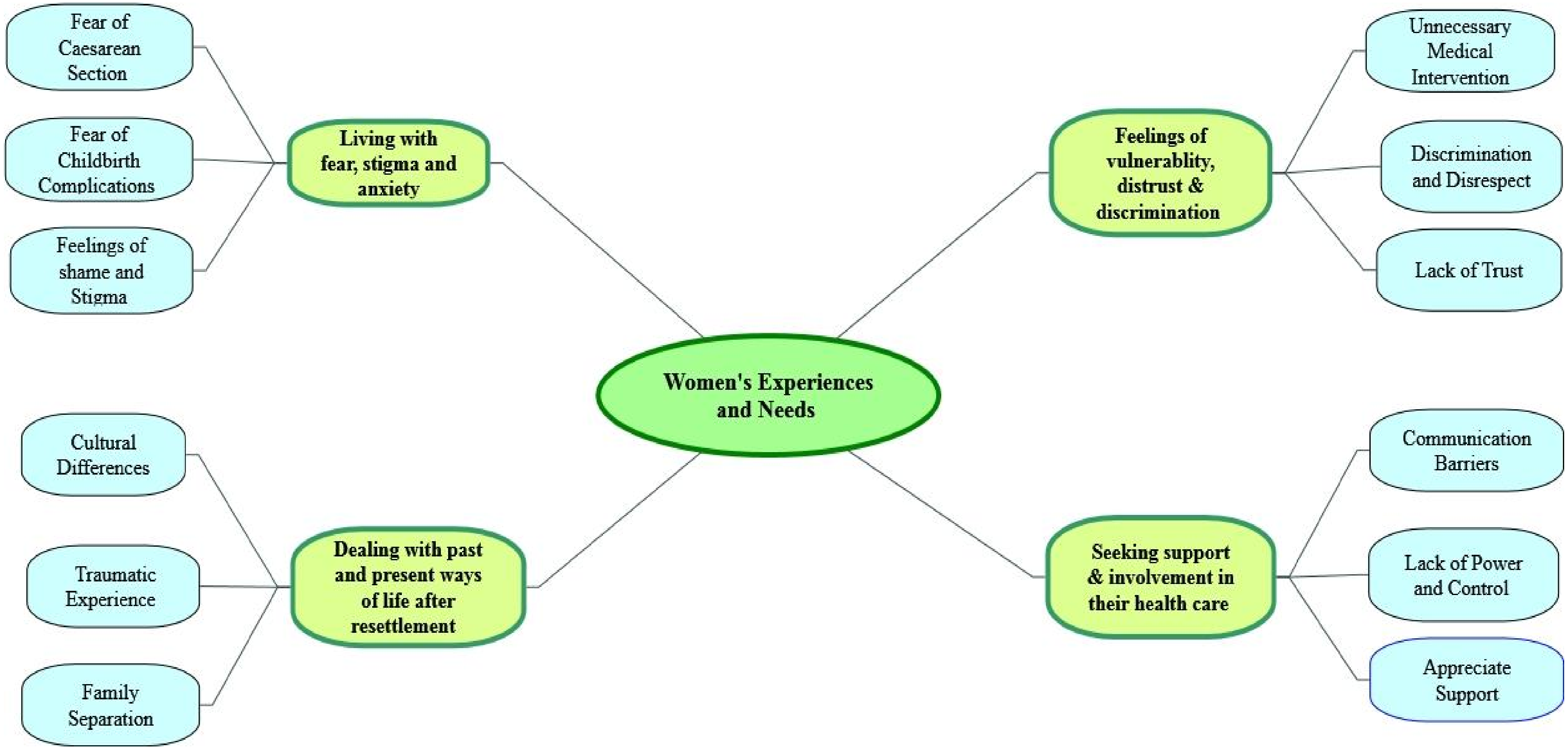


Figure 2: Themes derived from the analysis of the findings sections of the 16 included studies in the Meta-synthesis

Living with fear, stigma and anxiety

Women's fear and anxiety was associated with their experiences of FGM, being in or encountering an unknown environment or unfamiliar situation, fear of death or fear of complications resulting from pregnancy and childbirth.(Berggren, Bergstrom & Edberg 2006; Carolan & Cassar 2010; Chalmers & Hashi 2002; d'Entremont, Smythe & McAra-Couper 2014; Degni et al. 2013; Essén, Binder & Johnsdotter 2011; Essen et al. 2000; Lundberg & Gerezgiher 2008; Moxey & Jones 2016; Murray et al. 2010; Straus, McEwen & Hussein 2009; Upvall, Mohammed & Dodge 2009; Vangen et al. 2004) Three analytical subthemes emerged including fear of complications, fear of caesarean section and feeling of shame and stigma associated with FGM.

The fear of caesarean section was influenced by peers, religion and culture. Their fear was irrespective of whether they had a previous caesarean section. Being afraid of a caesarean section was also influenced by information given by health providers.(Chalmers & Hashi 2002; Degni et al. 2013; Essen et al. 2000; Vangen et al. 2004) For instance, a woman said:

> *'…The doctor frightened me by saying you may not have a healthy or live baby as a result of your FC (female circumcision). I told him I believe in Allah who determines my baby's life …I was very scared and afraid'.*
> *(Chalmers & Hashi 2002)*

Sometimes fear of unexpected complications or interventions meant women avoided seeking health care.(Ameresekere et al. 2011; Chalmers & Hashi 2002; Essén, Binder & Johnsdotter 2011) Some described approaches to avoid a caesarean section such as limiting their diet to reduce fetal growth (Essen et al. 2000) This is illustrated by a Somali woman's quotation:

> *'Here in London, when you have long suffering (prolonged labour)… the baby is taken by caesarean. Therefore, I am afraid that if I arrive early and take a little time … I will have to be operated … It is better to wait … Those who have given birth here have told me'.(Essén, Binder & Johnsdotter 2011)*

In some studies, women were afraid of a caesarean section as they believed it would take a long time for them to recover and would affect their ability to do daily housework,(Essén, Binder & Johnsdotter 2011; Essen et al. 2000) or their ability to become pregnant again.(Ameresekere et al. 2011; Berggren, Bergstrom & Edberg 2006)

However, there were women with FGM who had undergone an elective caesarean section as they believed they might have a traumatic and complicated vaginal birth because they had previously experienced complications.(Moxey & Jones 2016) For instance, one woman said:

> *'I thought because of the first experience, it was so horrible, I thought I could have a caesarean section, you know, I thought there's a chance of the tearing once again…I mean I kind of regret it. I wish I had a normal birth because I assumed a caesarean section is easier but only it's not easier. It's horrible!' (Moxey & Jones 2016)*

Feelings of shame, isolation, stigma and the loss of dignity were noted across studies, with stigma and shame being common emotions expressed by women.(Lundberg & Gerezgiher 2008; Moxey & Jones 2016; Murray et al. 2010) Women reported feeling different, unprotected and unsafe in the hands of health providers whom they perceived as strangers and incompetent.(Lundberg & Gerezgiher 2008; Moxey & Jones 2016; Murray et al. 2010) Feelings of shame and stigma sometimes hindered women's disclosure of FGM or any related complications they may have experienced, (Berggren, Bergstrom & Edberg 2006; Moxey & Jones 2016) for example:

> *'Kept it [FGM] hidden because I thought it was kind of like embarrassing…so I didn't tell her, I didn't say I was scared'. (Moxey & Jones 2016)*

Feelings of vulnerability, distrust and discrimination

Due to the social and emotional consequences of FGM, women felt vulnerable or helpless as they encountered the health system and health providers in a new country. They were traumatised by the negative judgments and racist comments they received, as well as disrespectful reactions by care providers.(Chalmers & Hashi 2002; d'Entremont, Smythe & McAra-Couper 2014; Degni et al. 2013; Upvall, Mohammed & Dodge 2009) Women perceived that they experienced both verbal and non-verbal abuse, and discrimination(Berggren, Bergstrom & Edberg 2006; Carolan & Cassar 2010; Chalmers & Hashi 2002; d'Entremont, Smythe & McAra-Couper 2014; Degni et al. 2013; Murray et al. 2010; Straus, McEwen & Hussein 2009; Vangen et al. 2004) for instance:

> *'They were very unkind and judgmental against my culture. They made me to feel unworthy to have a baby. They were sorry for my husband. One nurse said, 'a handsome young man to love a woman who cannot satisfy (him) sexually is a mystery to me'.(Chalmers & Hashi 2002)*

Women were sometimes exposed to unnecessary and unjustified medical advices or interventions. Some were advised by the doctors to be sterilised or undergo a caesarean section, or seek health care from a health professional from their own community who was familiar with FGM(Carolan & Cassar 2010; Chalmers & Hashi 2002; Essén, Binder & Johnsdotter 2011; Hill, Hunt & Hyrkäs 2012; Murray et al. 2010; Upvall, Mohammed & Dodge 2009; Vangen et al. 2004) as the following quote illustrates:

> *'They did not understand that I could possibly have a vaginal delivery and the nurse told me that usually our doctors are not comfortable unless it is a caesarean section'.(Chalmers & Hashi 2002)*

There was a lack of trust in providers' knowledge and skills relating to FGM. Women felt they had to guide health providers during childbirth because they believed their providers did not know how to manage FGM during pregnancy and childbirth and how and when to perform de-infibulation(Berggren, Bergstrom & Edberg 2006; Chalmers & Hashi 2002; Hill, Hunt & Hyrkäs 2012; Lundberg & Gerezgiher 2008; Straus, McEwen & Hussein 2009) for instance:

> *'I told the midwife that I was circumcised and sutured. The midwife had to cut and open the stitches during my delivery. I was worried and feared how she was going to manage it'. (Lundberg & Gerezgiher 2008)*

Dealing with past and present ways of life after resettlement

Women were frustrated in their attempt to fit their own culture into the Western context. Many women described how cultural conflicts or differences presented them with difficulties in dealing with the host culture(Berggren, Bergstrom & Edberg 2006; Bulman & McCourt 2002; Carolan & Cassar 2010; Chalmers & Hashi 2002; d'Entremont, Smythe & McAra-Couper 2014; Degni et al. 2013; Hill, Hunt & Hyrkäs 2012; Lundberg & Gerezgiher 2008; Moxey & Jones 2016; Murray et al. 2010; Upvall, Mohammed & Dodge 2009) for instance:

> *'I became a victim in Sudan already when I was 4 years old; I had no choice. Now I have to become a victim again after delivery, when the midwives refuse to re-suture me…. I understand that the law forbids them to do any suturing, but I am already injured; why do I have to suffer twice?' (Berggren, Bergstrom & Edberg 2006)*

Women talked about traumatic memories related to their experiences of undergoing FGM.(Berggren, Bergstrom & Edberg 2006) Some also referred to being re-infibulated during maternity care in the host countries despite this being illegal.(Berggren, Bergstrom

& Edberg 2006; Lundberg & Gerezgiher 2008) They compared their feelings of anguish and powerlessness when they underwent FGM to their experiences of health care in high-income countries (Lundberg & Gerezgiher 2008). For instance, a woman said:

> *'I was re-sutured twice. The second time was in Sweden. The midwife sewed without asking if I wanted or not. I was surprised, because I knew that it was illegal. After my third delivery, the midwife told me that the law prohibits re-infibulation, but the midwife stitched a little from each side as the opening was too wide'. (Lundberg & Gerezgiher 2008)*

The views of women indicated how deeply ingrained FGM is within their culture and personal identity.(Bulman & McCourt 2002; Chalmers & Hashi 2002) Some believed in the continuation of the practice(Upvall, Mohammed & Dodge 2009) and challenges to this confronted their own cultural norms. One woman said:

> *'We live in dangerous times. I do not think that circumcising the girls should be outlawed. They allow people to drink beer and alcohol, but they are saying circumcision is not good'. (Upvall, Mohammed & Dodge 2009)*

Seeking support and involvement in their health care

Women described their feelings of incapability and hopelessness when they were not included in health care decision-making processes and did not have a positive interaction with health care providers. Women felt a lack of control over their own bodies and their disengagement with health care resulted in further anxiety and stress. Communication and power relations were two analytical subthemes under this theme(Ameresekere et al. 2011; Berggren, Bergstrom & Edberg 2006; Bulman & McCourt 2002; Chalmers & Hashi 2002; d'Entremont, Smythe & McAra-Couper 2014; Lundberg & Gerezgiher 2008; Moxey & Jones 2016; Upvall, Mohammed & Dodge 2009) for example:

> *‘They had tied this belt so tight around my belly, it pained me and I tried to pull it away. I tried to tell the nurse, but she didn’t listen. She was angry and yelled at me that the heartbeat was indicating danger... So it ended like that, in a caesarean section. I still don’t know whether it was necessary to cut me’. (Vangen et al. 2004)*

Women talked about their exclusion from health care decisions that were ultimately made by providers(Lundberg & Gerezgiher 2008) and sometimes by family members.(Moxey & Jones 2016) At times, women were not asked if they had undergone FGM which contributed to their fear about how their birth would be managed. Some women seemed resigned to having decisions made on their behalf, even when the care providers’ reasoning had not been communicated to them(Berggren, Bergstrom & Edberg 2006; Chalmers & Hashi 2002; d'Entremont, Smythe & McAra-Couper 2014; Lundberg & Gerezgiher 2008; Vangen et al. 2004) for example:

> *‘I would have my appointments made for me and each time I went they would check or take what they wanted, and then I would leave without understanding what they had done. . . . I saw no special kindness. They would just do the job and go’.(Bulman & McCourt 2002)*

The language used by health care providers was often seen as scary or frightening.(Chalmers & Hashi 2002) This resulted in misunderstandings between women and care providers which led to increased fear as shown in the following quote:

> *‘I asked the doctor why I have to have a pelvic exam every time and with too many people and a long time on the table. He said ‘because you are very risky’. This caused unnecessary stress. I could not sleep at night…I did not have anyone to talk to and I thought I had stomach cancer’. (Chalmers & Hashi 2002)*

Just knowing the language was not always enough as women also reported making poor decisions about their treatment due to limited interpersonal communication or a lack of understanding about the information provided.(Chalmers & Hashi 2002; Straus, McEwen & Hussein 2009) Due to the sensitivity of the topic, interpreters did not always translate full conversations to health care providers.(Upvall, Mohammed & Dodge 2009) One woman said

> *'I wish I had a way to communicate with the doctor directly. There are things that sometimes I want to say or ask but I feel embarrassed saying it through a translator, especially on the phone'.(Upvall, Mohammed & Dodge 2009)*

Women tended to prefer direct conversations with providers rather than receiving written information.(Straus, McEwen & Hussein 2009) Furthermore, they valued oral information given by midwives despite the fact they did not always understand it.(Bulman & McCourt 2002) Women were sometimes overwhelmed and confused with the amount of FGM-related information given to them at once.(Berggren, Bergstrom & Edberg 2006; Chalmers & Hashi 2002)

> *'You say, "Oh yes, yes." Although you are not answering the questions, you just say yes ... "Are you alright?" "Yes." "Did you understand?" "Yes." "Yeah, and some of the women don't understand what the doctor said at all'. (Murray et al. 2010)*

Despite the negative experiences of some women, they commonly expressed appreciation for the support they had received within the health system.(Bulman & McCourt 2002; Carolan & Cassar 2010; Chalmers & Hashi 2002; d'Entremont, Smythe & McAra-Couper 2014; Degni et al. 2013; Hill, Hunt & Hyrkäs 2012; Lundberg & Gerezgiher 2008; Murray et al. 2010) They spoke positively about midwives who had knowledge of, and familiarity with, FGM as this made communication easier(Chalmers & Hashi 2002; d'Entremont, Smythe & McAra-Couper 2014; Lundberg & Gerezgiher 2008) for example:

> *'I was lucky when I met a midwife in Sweden who knew about circumcised women. This was a great help to make me feel secure because it was my first time to be pregnant and to live far from my parents and family'. (Lundberg & Gerezgiher 2008)*

Women were happy when providers treated them like other women and did not focus on FGM as an abnormality or ask them details about their sexual experience.(d'Entremont, Smythe & McAra-Couper 2014; Hill, Hunt & Hyrkäs 2012)

> *'…She didn't talk about it, and that didn't shock me. I didn't feel bad about it because I didn't hear the whisperings, there wasn't this movement of people passing by to look. She did her job …; she behaved as if everything was normal'. (d'Entremont, Smythe & McAra-Couper 2014)*

Discussion

This qualitative meta-synthesis found that women's maternity care experiences in high-income countries were influenced by fear, stigma, vulnerability and unfamiliarity with a new environment and culture Additional underlying factors affecting women's experiences included perceived discrimination from health providers', limited FGM-related clinical knowledge and cultural competence. This review also identified women's desire to be more involved in decisions concerning their care.

The findings of the review identify opportunities to improve the provision of quality maternity care. Quality care for this group of women should be multidimensional(Renfrew et al. 2014; Symon et al. 2016), and go beyond medical care alone to address social and cultural issues.(Symon et al. 2016) Quality maternity care should incorporate concepts such as woman-centredness, and cultural competence(Hulton, Matthews & Stones 2000; Van den Broek & Graham 2009) that are based upon an in-depth understanding of women's needs.(Berg, Asta Ólafsdóttir &

Lundgren 2012; Renfrew et al. 2014) One way that women's needs can be fully realised is by involving women themselves in the design, delivery and evaluation of health services. (Berg, Asta Ólafsdóttir & Lundgren 2012)

In our review, women with FGM who migrated to a high-income country were worried and frustrated by a mismatch between the information and resources they were given and those they wished to receive. All women should have access to timely and appropriate education and health information based on their needs.(Davies & Bath 2001) It is ideal if women themselves participate in a dynamic interaction where the information provided is consistently evaluated and modified according to their needs and the context of care.(Levy 2006; McKenzie 2004) Many resources have been designed in high-income countries to guide health professionals during consultations with women with FGM. However, these materials are often generic and tend to focus on information provision as opposed to communication with women.(HM Government 2016; Women and Newborn Health Programs 2016) Consistent with the findings of our meta-synthesis, women in other studies preferred concise information presented in plain language with the aid of visual communication tools such as short videos.(CoHealth 2015) Involving women in the design of such resources enables them to be contextually and culturally tailored to the specific needs of women in their host country. (Green 2012)

This meta-synthesis identified that all women despite their culture desired accessible, available and acceptable care. Where women received continuity of care from a culturally and clinically competent health care provider, they were more likely to trust the providers and share their cultural and health needs.(Sandall et al. 2010) A model of care specifically for women from vulnerable groups such as women affected by FGM should encompass continuity of care, educational interventions, and access to mental health support.(2012)

Continuity of care enhances health care providers' knowledge and confidence and enables them to be more aware of women's socio-cultural needs which results in women feeling empowered and achieving a greater sense of control over their own care.(McCourt & Pearce 2000) Further, providing access to a continuum of specialised FGM services, along with standardised guidelines for health providers will potentially contribute to improved perinatal outcomes for women affected by FGM.(Varol et al. 2016)

Misconceptions concerning the provision of culturally sensitive health care affects the delivery of necessary interventions such as deinfibulation for women affected by FGM. For example, in Norway health care providers assumed that not cutting infibulated Somali women during pregnancy was culturally respectful, whereas Somali women feared not being opened before they gave birth.(Johansen 2006) Despite the current policy discourse and global guidelines that promote a focus on respectful maternity care, cultural safety and clear communication, (HM Government 2016; NSW Kids and Families 2014; WHO 2016b; Women and Newborn Health Programs 2016) some health providers are either not aware of these guidelines or unable to put them into practice.(Leye et al. 2008; Turkmani et al. 2018) Cultural competence in an enabling environment with sufficient strategies and policies in place could potentially make a positive impact upon health outcomes for women with FGM, and provide equitable access to services across ethnic groups.(Beach et al. 2005; Clarke et al. 2015)

The findings of our review highlight the importance of shared decision-making. In our review, language barriers and miscommunication were highlighted as challenges to shared decision-making. Evidence shows that choices concerning a woman's pregnancy may be made by their primary clinicians without full consultation with the woman. (Origlia et al. 2017) Whilst women usually consider birth a natural and empowering process, (Baker et al. 2005; Gibbins & Thomson 2001) disregarding women's autonomy and involvement may disempower them,(Ali & Strøm 2012; Small et al. 2008; Small et al. 1998) thereby preventing women from engaging in shared decision-making.(Green 2012)

The findings of our synthesis provide insights from the perspective of affected women into issues concerned with the provision of their own care. Such insights are necessary to inform the provision of women-centred care, particularly for women from vulnerable groups whose voices are often unheard. However, a limitation of the review is that most included studies mostly focused on Somali women. Given the cultural diversity of women from different countries where FGM is prevalent, Somali women may report different experiences to women from other countries. In addition, women sometimes described their experiences of health services in general, rather than those specifically focused on maternity care. Finally, we only included articles written in English that met a limited inclusion criteria. As a result it is possible that some significant papers on FGM in other languages may have been omitted.

Conclusion

The findings suggest that future actions for improving maternity care quality should be focused on woman-centred practice, demonstrating cultural safety and developing mutual trust between a woman and her care providers. Meaningful consultations with women affected by FGM in high-income settings requires cultural sensitivity and acknowledgement of their specific circumstances. This can be achieved by engaging women affected by FGM in service design to provide quality care and ensure woman focused policy is developed and implemented.

Summary

This chapter has reviewed the qualitative evidence to explore the maternity care experiences and needs of migrant women with FGM in high-income countries. The review has identified gaps between what are known to be important aspects of quality health care and what migrant women who have undergone FGM perceive or experience as quality care. The dearth of knowledge concerning the maternity care needs of Australian women with FGM indicates that research is required to better understand the voices of these women..

The next chapter describes the study design, methodology and methods used to collect and analyse the data.

Chapter 3 Design and Methods

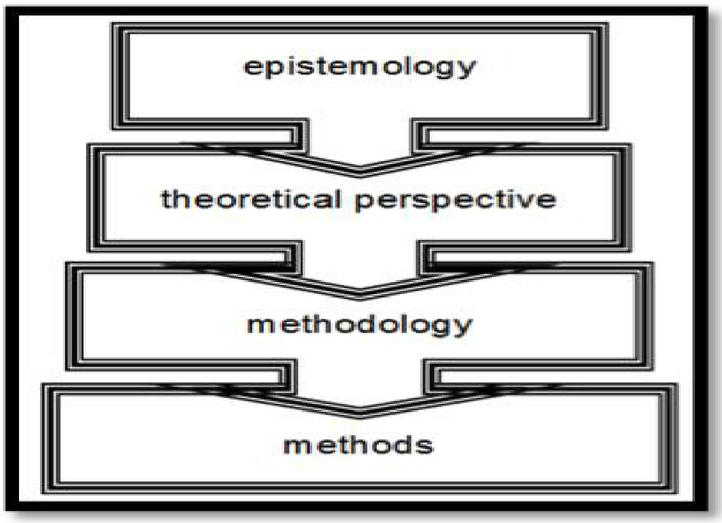
Introduction

This chapter describes the theoretical framework underpinning the study and the rationale behind the choice of philosophical perspectives. The methodological approach, including the methods for data gathering and data analysis are also described.

The Research Design Framework

I have used Crotty's theoretical framework (Crotty 1998) to guide my study design decision-making (Figure 3). Crotty suggested that researchers need to answer four fundamental questions: (1) How is knowledge understood in this research? (epistemology) (2) What is the related philosophical stance that is articulated in the research questions? (theoretical perspective) (3) What informs the choice of the methodology? (systems of methods) and (4) What would dictate the methods? (data gathering techniques) (Crotty 1998, pp. 2-5). Crotty (1998) proposes that the epistemology, theoretical perspective, methodology and methods are inter-reliant elements; and a decision to select a particular methodology will, for example, affect the selection of the appropriate methods (see Figure 3). King and Horrocks (2010) also argue that the epistemology, methodology and methods are all connected and cannot be viewed in isolation.

Figure 3: The inter-reliant of four elements of Crotty's (1998) framework



The table below illustrates the choice of the epistemology of constructivism and the philosophical perspective of Interpretivism and Critical Inquiry for this study, as per Crotty's (1998) framework. (Table 1)

Table 1: Schematic outline of the theoretical framework for this study based on Crotty (1998)

Epistemology	**Theoretical Perspective**	**Methodology**	**Methods**
Constructivism	Interpretivism Critical Inquiry	Appreciative Inquiry	Sampling, public partnership in research Semi Structured Interviews Focus Group Discussions Field Guideline Self-Reflection/Field Notes Thematic/content Analysis

Epistemology

Ontology and epistemology are two main branches of philosophy that shape our understanding of the world. Ontology is the study of the nature of reality, the concepts that make up our existence and how they relate. Epistemology focuses on our perceptions or understanding of the knowledge that is shaped by that reality (Creswell 2009; Maxwell 2012). Crotty's theoretical framework (Figure 3) demonstrates how these branches of philosophy relate to determining the theoretic perspective, methodology and methods of a research study. While ontology is not clearly demarked, Crotty argues that the epistemological position will be informed by ontology in some way, however it is challenging to differentiate ontology when discussing research due to the complex nature of this question (Crotty 1998, pp. 10-11). King and Horrocks (2010) also agree with this view arguing that ontological and epistemological issues often arise together. Similarly, Higg's (2001) philosophical stance is based on what counts as knowledge and how this knowledge can generate what is called 'truth'. Creswell (2007) has a similar view on the research process which is based on Crotty's framework. However, Creswell argues that ontology should take an independent stance toward the science of knowledge. Burrell and Morgan (1979) also suggest epistemology is independent from ontology, with human nature and methodology as the philosophical assumptions.

Epistemology is defined as a way of 'understanding and explaining knowledge underlying the research' (Crotty 1998, p. 8). It is also known as the association between the 'knower and what would be known' (Guba & Lincoln 1994, p. 108) or the relationship between 'researcher and that being researched' (Creswell 2007, p. 17). Crotty outlines the epistemological positions of objectivism, subjectivism and constructivism in his theoretical framework (Crotty 1998). Objectivism is based on inherent meaning of the objects and it can be quantified or measured. In contrast, subjectivism suggests that it is the researcher who prescribes the meanings to the objects rather than the result of direct interaction between what is being researched and researcher. In constructionism, the meaning is constructed by the objects (what is being researched) and the subjects (researcher) and it might be different for the same issue (Crotty 1998). Constructionism is the most appropriate epistemological position for my study given I am examining the direct interaction between ‘object’ and ‘subject’.

Constructionism, also called social constructionism, is an epistemology embodied in many theoretical perspectives (Crotty 1998) and often combined with interpretivism (Creswell 2007). With constructionism, the whole reality depends on constructed meaning developed through research and meanings are directed towards certain objects rather than natural facts (Creswell 2007). Crotty’s view is that social constructionism tries to realise what is actually real and what is defined as real by society. Based on the view of constructionism, the existence of most realities in this world are created by people and society rather than derived from any true rationality. Therefore, the meaning might be changed by the way society defines it and its meaning will be different by culture or context. For example, in the context of my study, women from a different society or culture may construct different understandings of quality maternity care in Australia in contrast to what has been reported by health professionals or defined by health care decision makers in the host society. Vygotksy (1978) and Bruner (1987) believe that the societies and cultures we live in provide us with the tools to perceive or construct the meanings. Despite having our own individualised perceptions, meanings originated from a social context. This approach is appropriate for my study as I sought to understand the maternity services experiences and needs of women as well as their perceptions of quality maternity care in a different context to their home country.

Theoretical Perspective

Theoretical frameworks provide a map to explain why the world is the way it is (Strauss 1998). Maxwell (2012) argued that a theoretical framework is the core of social research and must be constructed and integrate the ideas of others. However, the researcher needs to build up their own structure, based on existing theories and relevant research (Maxwell 2012).

Theories are formulated by applying philosophical principles with a methodology, a study object and social group agreement and interest. The relationship between these principles forms a body of knowledge to describe, explain, foresee and control (Craig 2009).

The theoretical perspectives are the result of a particular epistemological position (Creswell 2009; Crotty 1998) which provides a context for the research, such as positivism, interpretivism, critical theory, feminism, and other divisions, such as phenomenology and hermeneutics. Crotty (1998) posits that these philosophical perspectives provide a structured approach that is necessary to allow researchers to make sense of the extensive number of research approaches.

These issues are complex and require careful consideration. Abbott (2004) argued that philosophical views in a complex field, such as social science, need to be a combination of different views rather than just a unified view. Similarly, Hassard (1991) also suggests that the use of multiple philosophical paradigms in research would generate more insights and empirical sets of data. The compatibility of such multi-perspectives also needs to be assessed (Abbott 2004). My study aims to capture women's stories and narratives and I recognise that issues such as ethnicity, culture, gender, and the circumstances of women's social and political structures shape their experiences differently and affect their views and needs. Therefore, a multi-paradigm approach was required involving interpretivism and critical theory. I describe each of these paradigms in the next section.

Interpretivism

Interpretivism is the first and dominant theoretical perspective for my study and is informed by constructivist epistemology. Interpretivism, with its basis in constructionism, informs a variety of methodologies including appreciative inquiry, ethnography, phenomenology and grounded theory (Creswell 2009; Crotty 1998).

Interpretivism supposes there are no implicit laws to discover but just models to interpret natural events (Crotty 1998). Interpretivism focuses upon the meanings which deal with the interpretation of natural laws and science (Creswell 2007; Crotty 1998), whereas positivism rejects other 'ways of knowing such as through interpreting meanings and intuitive realizations' (Charmaz 2006, p. 5). Interpretivists argue that individuals interpret situations in their mind, therefore the approach supports researchers to conduct in-depth explorations of individuals' perceptions, their perspectives and the way in which people construct meaning (Gray 2014). The interpretivist researcher enters the field with the prior insight of the research context with the assumption that there are multiple and complex knowledge systems and meanings about the nature of what is perceived as reality (Hudson & Ozanne 1988).

My study involves understanding and interpreting the meanings, motives and reasons attributed to behaviours by women that are not only constructed by them based on their social realities but also within the social context of each woman. Those meanings can vary across, and even within, individual women and change according to their circumstances. In order to obtain a sense of women's experiences and what resources and support they require I needed to enable and support women to talk. In doing so, the participant's understanding of their maternity care was jointly constructed and then interpreted to discover the underlying meaning. The women in my study, as well as myself as a researcher, brought personal views and constructed meanings to particular issues such as quality maternity care. This means that the use of an emergent and collaborative approach such as that afforded by Appreciative Inquiry is consistent with the interpretivist paradigm (Hudson & Ozanne 1988).

Critical theory

Critical inquiry is a social theory that originated from Marxist philosophical concepts in the 18th Century (Schwandt 1994; Wilson & Magalhães 2016). Marx believed that all changes in society are grounded on social realities (Wilson & Magalhães 2016). Later on, other sociologists (Max Horkheimer, Theodor Adorno, Erich Fromm, Walter Benjamin, Jürgen Habermas, and Herbert Marcuse) from the Frankfurt School in Germany built up and integrated their own perspectives into the Marxist tradition. Critical theory is concerned with the social, ideological and historical forces that shape and constrain society and how structures can be changed (Adorno 2001). Jürgen Habermas emphasised that critical inquiry goes beyond a philosophical concept and can take the form of a communication tool that can enable people to speak out about issues they have in society, voice their concerns and defend them rationally (Crotty 1998). Critical theory, therefore, empowers people to reflect upon and critique society, and understand their opinions, needs and experiences as the product of a political and social context (Wilson & Magalhães 2016). Critical inquiry can be understood as a liberty research paradigm and critical theorists take use of this approach to release people from the oppression directed towards them due to their race, social class, gender, and religion. It gives voice to those voiceless which can benefit the deprived and marginalised in the society by critiquing and uncovering injustice and bring changes in the society (Asghar 2013).

In the context of my research, the voices of women with FGM are often missing from health service narratives and research. The evidence from my systematic review showed that there was a combination of helplessness, lack of trust on health providers' competency and emotional disturbance that makes these women feel vulnerable, stressed and stigmatised (Turkmani, Homer & Dawson 2018). Therefore, the use of critical theory can empower women to speak up and enable them to engage in health improvement processes. Such an approach can increase women's involvement and sense of responsibility in the prevention, protection and promotion of their own health and the health of society. This process of engagement also allows women to have a sense of control and power in delivering their messages and ideas without fear or feeling dominated by the views and decisions of others. A critical theory approach may enable women to lead the conversation to define their issues and, recommend solutions.

Methodology

Methodology refers to the overall strategy or plan of actions for conducting research (Creswell 2007). The aim of this study was to explore the maternity care experience and needs of women with FGM who have migrated from different countries and now live in Australia. The study employed a qualitative methodology in order to focus on human experiences and the way they react to the world in which they live in (Bazely 2013). The study focused on the discovery of participants' perspectives and experiences within the healthcare system using a qualitative methodology for this exploration.

There are a number of different qualitative designs to facilitate an exploration into participant's experiences (Chenail 2011). Specifically, Appreciative Inquiry (AI) was chosen over other qualitative methodologies, such as phenomenology, as I wanted to move beyond the first person perspective and a focus on the structure of the experience to identify opportunities for a shared vision for the future by engaging others in strategic innovation (Bushe 2011). In addition AI is a collaborative approach that can be employed with individuals and groups of participants to facilitate and open up a positive conversation about their experiences, their needs and ways to work together to address them (Trajkovski et al. 2013a). AI is a qualitative research methodology that has 'naturally occurring' characteristics as people may turn towards certain thoughts and images which capture their interests rather than lead by the researcher and it is open-ended, allowing a flexible approach to be taken depending on the needs of the participants (Reed 2007). I wanted to engage the participants in the vision process and AI matches these aims.

The AI approach is underpinned by social constructionism and critical theory. The principal of social constructionism is similar to that of AI. Both approaches want to make sense of people's experiences to 'create true changes' (Cooperrider & Whitney 2005, p. 50). Constructionism and AI are based on processes of social interaction and interpretation of people's reality and an appreciation of what has worked well and what could go into the development of future actions and changes (Reed 2007). The integrated use of AI and critical theory also tries to focus on the positive experiences of people who are voiceless and dis-empowered and recognises the complexity in human experiences (Grant & Humphries 2006; Reed 2007). The relationship between critical theory and AI is the development of confidence and assertiveness in women to be empowered and actively involve and contribute to the improvement of quality services as users of maternity services (Edwin 2013). The use of AI and its link with my study is elaborated in more detail in the next section.

Appreciative Inquiry

Appreciative Inquiry (AI) was developed by Cooperrider (1986) and first used as a tool for organisational change and development (Cooperrider 1986; Cooperrider et al. 2000). The benefits of AI as a research tool or approach has been less debated across literature than other methods (Reed 2007). However, recently AI has been used effectively as a qualitative approach in health care settings (Chenail 2011; Trajkovski et al. 2013b). For instance, it has been used to explore patient's experience of clinical healthcare (Chenail 2011) and to address complex needs of families and children in primary health care (Carter et al. 2007). As another example, McAdam and Mirza (2009) used AI to describe the experience of marginalised youth engaged in drug and alcohol misuse and implications of positive stories on health and social well-being. Similarly, Moor and Charvat (2007) used AI and its challenges as a strategy for behaviour change among African and women from low-socioeconomic. In UK, AI has been adapted to explore midwifery services and provide suggestions for positive changes in midwifery leadership, women's involvement in maternity care and promote equity of care (Lavender & Chapple 2004).

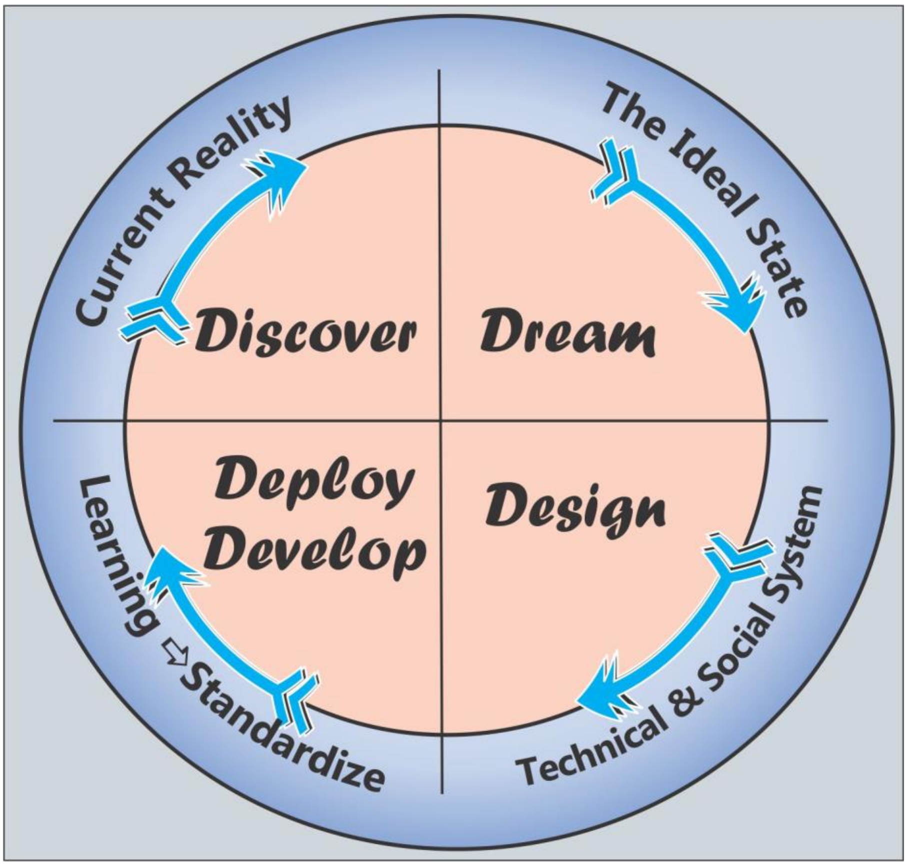
The AI process not only supports to create a positive image of the future but also enables a dynamic promise for change and a sense of hope among groups of people (Michael 2005). AI focusses on people's ideas, values and takes a positive view on events and experiences rather than concentrating on problems (Reed 2007). Cooperrider believed that emphasising the best moments of the past and present enables people to move towards what gives them positive images of the future (Cooperrider et al. 2000).

According to McArthur-Blair (2013) and Trajkovski (2013a), the AI '4D model'(Discovery–Dreaming–Designing–Destiny) starts by appreciating or the

‘Discovery’ phase. This first phase is about learning, discovering the best moments and memories through storytelling. The second phase, ‘Dreaming’, builds on these moments to visualise what the situation of interest might be look like in the future. The focus of the AI process then moves to ‘Designing’ the plan for future changes and what actually need to be done to make their dream a reality (Phase 3), and finally, agreeing on each individual’s position in achieving that plan called ‘Destiny’ (Phase 4) (Figure 4).

The use of AI’s 4Ds in this study offers a way of identifying possible solutions to improve the maternity service for women with FGM. The use of AI is novel in directing attention to a strength-based approach that can support marginalised women to engage and share their views. Furthermore, the rigorous use of AI in my study provides insight into the diverse perspectives of women’s maternity experiences and needs.

Figure 4: '4Ds' Cycle of Appreciative Inquiry http://www.lmmiller.com/the-process-of-change/whole-



system-architecture/ My research differed from the traditional model of AI which is purely based on the needs of participants (Trajkovski et al. 2013a). Instead, my project involved one or two points of contact with women, the first time on an individual basis and the second time as part of a group. I covered all the ‘4D’ phases during individual interviews, however, I put more emphasis on ‘Designing’ and ‘Destiny’ during the group discussions. In the light of my research aim, I developed a list of issues that needed to be addressed and made them into appreciative questions and used this as my field guide during interviews and focus group discussions (Appendix 1).

Discovery and Dream (Phases 1 and 2)

The discovery phase of the process for my study employed storytelling as a means of encouraging women to focus on positive aspects of the care they had received. Women were asked, for example, to identify their best or proudest moments and experiences when they were pregnant and gave birth to their baby in Australia and what had been satisfactory about these moments or experiences.

The dream phase encouraged women to project their vision of what they regarded as quality maternity care and what they would wish in the future for themselves or for their daughter, sister or other women more broadly. I reminded them there were no restrictions and encouraged them to express a bold vision. To make it easier for women to think and dream, I explained that they should imagine that there are ample resources, including skilled staff, equipment infrastructure and political will for this vision to be achieved.

Design and Destiny (Phases 3 and 4)

The design and destiny phases of the AI cycle challenged the women individually and as part of a group to develop a future plan for what they need or wish to happen to move towards their dreams. These final phases also encouraged them to identify a possible role for themselves, providers and government in supporting that plan. Finally, the destiny phase of the AI cycle engaged the women in discussing and identifying the means of supporting the plan they have developed to make it feasible and sustainable.

Methods

The methods used in my study were informed by the methodological approaches and theoretical perspectives mentioned earlier in this chapter. The methods are presented in this section including the study setting, ethical considerations, the participants and their recruitment, the processes of data collection and the analysis.

Study Setting

This study was conducted in Western Sydney, New South Wales (NSW). NSW has more than 7.7 million population, of which about 28% of them are born overseas (ABS 2017). Around 3.9 million of the NSW population are female and nearly 40% of women giving birth each year are born overseas; 5.3% of them were born in the Middle East or Africa (Centre for Epidemiology and Evidence 2017). Western Sydney has a highly diverse and multicultural population and comprises the majority of Sydney’s population (NSW government 2015). According to the NSW Mothers and Babies report (2017), the largest number of non-English speaking women who gave birth were residents of Western Sydney area. Therefore, this study was conducted in Western Sydney on the basis of this being an area of high density of the target population (women who had experienced FGM) to increase the likelihood of being able to recruit women from the study population.

Ethical Considerations

This research was guided by the principles of ethical conduct for research in human subjects (National Health and Medical Research Council, 2007). Ethical approval (UTS HREC REF NO. ETH17-1525) was obtained from the Human Research Ethics Committee of UTS in August 2017 prior to the recruitment or data collection process (Appendix 2).

Ethical considerations for this project were of particular importance as the migrant women with FGM often feel vulnerable, stigmatised and marginalised (Berggren, Bergstrom & Edberg 2006; Chalmers & Hashi 2002; Essen et al. 2000). The design and conduct of the research was with direct consultation with experts in this area including the NSW Education Program on FGM, No FGM Australia, a non-governmental organisation and an independent activist and advocate who is a survivor of FGM. I had previously worked with these experts on an FGM project for two years and as a result, had considerable pre-requisite knowledge of the cultural aspects of this practice. In addition, a member of the community was involved throughout the process and guided the development of the research tools, assisted with recruitment of the study population and ensured that the project was conducted in an ethical and culturally appropriate manner.

A written information package was given to women to invite them to participate. The information sheet outlined the aim and objectives of the research and the description of the processes including the interviews and/or focus groups. I provided information about myself, my supervisors and the ethical approval from UTS, assured them of the confidentiality of their information and their identities (Appendix 3).

Participants signed the consent form prior to the commencement of interviews or group discussion (Appendix 4). The consent form included participants' rights and responsibilities, assurance of confidentiality and information regarding the risks and benefits of the research so that individuals may freely accept or decline participation. Interview and focus groups data were audio recorded. Participant anonymity was assured by allocating a code to the woman's name. The woman's codes and their names were stored separately so that they cannot be combined. I am the only person who knows the identity of the participants. This assurance of anonymity enabled women to feel free to share their experiences without fear of any consequences. All interview transcripts and audiotapes have been kept in a secure computer that is password protected. The data will be disposed after seven years of the completion of the study.

Due to the confronting nature of this study, it was expected that women may be exposed to a degree of psychological discomfort or distress during interviews and group discussions. Therefore, a clear distress protocol was developed (Appendix 5). Participants were assured that should they become distressed during the study, counselling services and referral to appropriate mental health provider were in place to minimise the risks of discomfort or distress (McCosker, Barnard & Gerber 2001).

Participants and Recruitment

I recruited women who had first-hand experience and knowledge about the subject matter by having personal experience of the Australian maternity system (Binder, Johnsdotter & Essén 2012; Boote, Baird & Sutton 2011). The participants were English-speaking migrant and refugee women who were personally affected by FGM and lived in Sydney. The women must have given birth in Australia in the last ten years, or be currently pregnant.

Over the duration of five months of data collection (October 2017-February 2018), I conducted 23 individual interviews and four focus group discussions with women. Due to stigma and shame associated with FGM in high-income countries and the sensitivity of the topic (Asma, Trister & Nicole 2018; Johansen 2006), many women may not disclose their FGM to outsiders. Therefore, it was challenging to reach out to these women and encourage them to participate. A form of convenience sampling called chain referral sampling was employed to approach potential women (Heckathorn 1997). This method of sampling is useful for recruiting participants in research where the topic is sensitive or in populations that are stigmatised and hard to reach (Biernacki & Waldorf 1981; Penrod et al. 2003). For instance, a chain referral sampling approach has been utilised successfully in studies with drug users, sex workers and people who are living with HIV (Duff et al. 2009; Ribeiro, Sanchez & Nappo 2010; Syvertsen et al. 2012). Chain referral sampling was also a suitable approach for my study because the target population may know each other within their community and could be a source of referral to expand the sample (Heckathorn 1997). However, in my study, a research assistant (RA) who was also a member of the community facilitated the initial contact with women through her network and consequently, referred women to me who in turn referred other eligible women within the community.

Evidence shows that engaging community members in research can facilitate the recruitment of the study sample, bring unique insights and improve the overall quality, relevance and appropriateness of the research (INVOLVE 2012). I approached the NSW FGM Education Program to connect with potential participants. With the assistance of the Community Education and Development Officer at the NSW FGM Education program, I identified a local woman with a similar background as the research assistant (RA) to help with participant recruitment. I provided training for the RA to familiarise her with concepts of human research ethics and orient her to the study tools for data collection. She also helped me to plan fieldwork activities and ensure that the data collection and data interpretation were culturally appropriate.

Data Collection

The data were gathered through semi-structured interviews, focus group discussions (FGDs) and field notes over the course of five months. The use of different methods of data collection helps to provide a deeper insight into the same issue by mixing different views and perceptions (Barusch, Gringeri & George 2011). Interviews and group discussions were guided by questions (Appendix 1) in accordance with concepts of AI that were flexible enough to enable an exploration of ideas that women raised (Gill et al.

2008). Before the interviews and group discussion, I read through the field guide to remind myself about the points that needed to be covered. All the interviews and group discussions were held in an environment that was convenient to the women and was quiet, where they could speak without interruption such as libraries, private rooms, community centres and the woman's home.

Appreciative Inquiry provided a structure to build rapport with study participants to explore their stories in a positive manner (Reed 2007). The process began by engaging women in a dialogue or open discussion to explore their experiences and to talk about the strengths of the maternity services in Australia. By focusing on imagining quality care experiences, they offered a new plan for the improvement of maternity services. The interviews and FGDs were audio recorded and transcribed verbatim. The sections below explain how each aspect of data was collected.

Individual Interviews

The majority of the women I interviewed were recruited by the RA. The RA provided the initial information about the nature of the study and why their participation was important and sought preliminary consent from those who agreed to participate. I then telephoned women prior to the interviews and provided them with further information and an opportunity to ask any questions.

Interviews were held at a time and place convenient for women. We offered small gift cards as compensation for their time and travel to the interview location. Once women had agreed to participate, I collected demographic information prior to the interview. All the interviews were conducted in English.

Establishing rapport and mutual trust during the interview process was necessary in order to ensure that participants feel comfortable and relaxed enough to reveal their experiences and tell their stories (Atkinson 2001; Creswell 2009). I started the interviews with an introduction and explanation of the study and an informal chat to make women feel comfortable. Despite the fact they had already received the information sheet and signed the consent form, I reminded them that the interview was voluntary and they could stop at any time if they felt uncomfortable or did not want to answer the questions. The interviews took 45-60 minutes and women were encouraged to provide concrete and recent examples and reflect on their own experience rather than giving abstract answers. However, women were given the freedom and opportunity to describe their experience as they wished and I generally allowed them to continue.

Focus Group Discussion

The focus group discussions were conducted to further explore the participants' experiences. The group discussions enabled participants to share their experiences in a way that generated innovative ideas and enabled the development of deeper insights by exploring meanings, perceptions and interactions (Kitzinger 1995; Stringer & Dwyer 2005). The group discussion for my study tried to draw out women's shared recommendations, advice and future actions to improve the maternity services.

Women who were able to participate in the FGDs indicated their agreement when they signed the consent form for the individual interviews by ticking a box and, later on, the RA confirmed their participation. In total, I conducted three focus groups with women who were able to speak English. The focus group participants were the same women who participated in individual interviews. All group discussions were held in community centres except for one, which was held in a quiet corner of a local park. I conducted the group discussion, however we excluded that group from the data analysis and only used the data as discussion points and later reflections.

The format of the semi-structured field guide for the group discussion was similar to the individual interviews and was used as a prompt to cover all key areas of focus. The atmosphere of the groups was kept informal and I prepared food and drinks for the women attending and offered gift cards to thank them for their contribution.

Planning a focus group discussion was the most challenging part of my study as I was concerned that women may not be comfortable to sit in a group and share their stories about such a sensitive topic with people outside their culture. I decided to conduct each FGD with women of the same background so they may be more likely to participate. There were at least five women in each FGD except for one, in which eleven women from a Somali background participated. All the conversations and discussions were audio recorded with the permission of participants.

Field Notes

During the study, I kept a diary of field notes, which included my reflections and assumptions about the data collection, my interactions and relationships with study participants and my experiences as a researcher. The ultimate objective of field notes was to capture thoughts, interpretations and meanings that might be forgotten or missed (Craig 2009). This was an important source of information which helped in the interpretation and analysis of the data and provided for greater depth and understanding of the situation (Craig 2009).

Data Analysis

According to Creswell (2009), researchers need to follow systematic steps for data analysis, however the steps needs to be undertaken in several levels and begin with the detailed analysis before moving towards the more generic (Creswell 2009, p. 184). In contrast, Braun and Clarke (2006) argue that the process of data analysis starts with identifying broad categories and then these are grouped into relevant themes and sub-themes, bringing together participants' ideas and experiences in more detail to form a comprehensive picture out of their collective experience (Braun & Clarke 2006). I followed Braun and Clarke's (2006) approach to qualitative data analysis because it offered a way of analysing the data according to the 4Ds of AI in the first instance followed by a closer analysis of women's experiences as maternity service users. However, I remained open to any additional themes that emerged from the data.

I began my data analysis with verbatim transcriptions of the data (Stuckey 2014). Transcribing the data myself not only enabled me to become familiar with the data but also gave me the opportunity to become immersed in the data through repeated and careful listening (Bailey 2008). I was, therefore, able to reflect on the tone, voices and emotions of the participants and consider possible multiple meanings (Stuckey 2014). Due to the different accents, overlaps in conversation and distracting noises (e.g. babies, planes, building construction) it took approximately four hours to capture the fine level of detail per transcript. Five of the transcriptions were randomly re-checked with the RA and, if needed, we telephoned individual participants to check the transcription and to seek further clarification on the meaning of the participant's expression. This helped to avoid errors that may have had a negative impact on the quality of the data (Davidson 2009; Mero-Jaffe 2011).

The second step in the data analysis process started with cleaning, organising and then preparing the transcripts in print format. I printed out transcripts and coded sections of data within them under each phase of AI (Appendix 6). This enabled me to reflect on overall meanings and general ideas through familiarity and making sense of the data (Craig 2009; Creswell 2009).

Data were then exported into the NVivo qualitative data management software to facilitate extraction of the significant statements and undertake the categorisation into patterns and major themes and sub-themes (Aronson 1995; Woods 2002). In the third step, with use of the NVivo, I categorised the coded data under the research questions which allowed me to look at relationships and refine the data into a more organised and manageable way (Appendix 11, NVivo mapping feature). Using the NVivo software provided the capacity to manage, access and analyse my data and keep a viewpoint on all the data without losing critical themes of transcript texts (Bazeley 2002). I continued with more detailed coding through selective coding and axial coding which supports the principle of AI (Craig 2009).

In the fourth step, I translated the major findings into themes that reflect the women's perspectives and provided a description on the woman's narratives. The final step of data analysis involved interpretations of data and meanings of findings and from there I could draw recommendations on what were the next steps and conclusions (Creswell 2009).

Study Rigour

Measures were put in place to ensure the validity and trustworthiness of the study (Lincoln & Guba 1985). I considered Lincoln and Guba's (Lincoln & Guba 1985) criteria for scientific rigour in qualitative studies including credibility, transferability, dependability and conformability.

Developing mutual trust with the participants was important to have rich and credible data (Beebeejaun et al. 2014; Charmaz 2006). Having a pre-existing relationship with the study participants is likely to build up such trust and benefit the study (Burns et al. 2012). Burns et al. (2012) argued that involving an insider perspective in the research process offers many advantages, such as quicker access to the targeted communities, timely rapport building and a better understanding of the culture and effective coordination of activities. Therefore, I involved a member of the community (the RA) to recruit women from those communities where she previously had a connection with, and previously worked with them, as a bi-lingual community worker. The RA had a strong network with diverse groups from the target population, which meant I could gather data from a diverse population.

I had on-going consultations with my supervisors to ensure other perspectives were incorporated into my study and to test my ideas and interpretations (Shento 2004). We also had regular peer meetings with other PhD students to discuss our methods, share our concerns and ask questions about the work of other students in a similar area. This strategy helped me to explore and learn from others' perspectives (Barusch, Gringeri & George 2011).

The data and data analysis strategy and procedures have been documented and elaborated through reflexive field notes to ensure dependability. I have presented all aspects of the research process, methodology and data collection and data analysis so that they can be repeated in a similar setting. I also presented the study at local and international academic conferences and received feedback and questions. This enabled me to refine the analysis and the thinking behind the work.

I ensured the transferability of my study in other settings by describing the context and methodology. I have provided a clear and detailed description of the study context, participants, data collection and data analysis. In addition, I have provided a transparent explanation of AI phases and my challenges, which may allow the reader to judge the transferability.

The degree that the results of a study are confirmed by others is called conformability (Lincoln & Guba 1985). I used several strategies to advance the conformability of my study such as checking and re-checking of the data, self-reflexivity, and being aware of potential biases. I have put together my reflection in a section as part of my thesis titled 'researcher reflection' in the last chapter.

Self-reflection: Centring women in research

I was aware that the whole process of my study from its inception to end could trigger and influence my own personal emotions as a health professional, as a woman and as a refugee from Afghanistan who has had a long history of witnessing the violation of women's rights. I had mixed feelings undertaking this research project. Initially, I felt guilty as my research may involve women sharing unpleasant events from their life and I did not want to create further trauma. I found it emotionally distressing to listen to the painful and disturbing stories of the women. I thought I could take a break from the intensity of those emotional moments after data collection. However, as data analysis was on-going, I needed to go over and over those stories and listen to the tape recordings and all the memories and emotions came back and kept me awake at night. I felt that I was weak for not being able to control my emotional feelings. Gradually I learned that the solution for me was not to suppress my emotions. As I moved on in my study, I made it clear to myself that I am also a participant of this study, like the women themselves. I have a story like any of them but my story is separate from them and in that way, I released my own anger and judgment. I wanted the women to know that their voices are heard with my soul, heart and my mind and that I will make every effort to reflect their experiences. I wrote all these thoughts and issues down and kept all my feelings in a journal, which I found to be a useful tool to meditate upon the emergent findings and to heal myself. My journal helped me to focus on the women's stories and learn from their experiences which is the ultimate goal of this research project. I also shared my feelings and reflections with my peers and supervisors and this helped me to overcome some of the feelings and put them in perspective.

I found the process of AI to be an empowering and useful tool for listening and learning through sharing experiences I realised that the process of storytelling is like a healing process, and a few of the women even invited other women to take part in the study to gain some sense of healing. I learned through the AI approach, that women, even with the most adverse experience of maternity care, can find some positive moments to draw upon. To me, this was the best part of this methodology with a group of vulnerable women. However, the challenging part of this practice was that the initial mindset of women was negative; taking a positive or appreciative approach while moving the conversation back towards their past positive experiences was not always easy. In my study, I was interested to explore women's needs as well as the barriers they faced in their encounters with maternity services. I also wanted to know how culture and contextual differences and personal behaviours affected or re-shaped their maternity experiences. Women usually started their stories with complaints about their care or their poor experience. In these instances, I let women continue without interrupting and waited until they finished. The challenging part was that I wanted to also focus on their positive experiences. However, many or most aspects of their experience were negative. When women had finished their initial story, I tried to get them back on track by relating their information and by taking an appreciative perspective. For instance, in one case, I said to the woman, ‘at least someone smiled at you when you got there’. These simple reflections usually altered the tone of the conversation and shifted it towards a more positive focus. I found this strategy to be very effective even when women were relating very negative experiences and had difficulty staying or being in an appreciative mode. By giving the impression to the women that I understood nothing about the realities of their experiences, I maintained an even balance of power relationship, supporting them to make sense of their experiences, while enabling them to share their stories without fear of judgement.

As the study progressed and I built a rapport with the women, I realised, as a health professional, that there is a considerable gap in the general knowledge of affected women about FGM. I felt anxious about moving on without correcting their knowledge about FGM or not providing them with the right information. I started educating women about types of FGM and its health consequences. I used some of the graphic materials and flipcharts from the NSW FGM program and drew pictures on paper to communicate my messages. Despite time limitations, women were very interested and stayed on after the interviews and focus group discussions to learn more about FGM.

My experience of using AI in my research was very rewarding. This was the result of the collaborative nature of this method. In several cases, women identified the process as enabling, therapeutic and unique. They appreciated the opportunity to share their stories and their experience openly in a supportive environment. This was an extraordinary and empowering experience for me as a researcher to be able to bring out the positive side of their experiences. I was inspired by the level of honesty, hope, courage and resilience of these women. I believe the greatest outcome from this study, in addition to my research training and contribution to new knowledge, is the personal compassion I developed for women and their distinct and exceptional experiences. AI is an effective approach that would work well across different cultures, sensitive topics and with traumatised participants.

Finally, presenting such a complex and holistic phenomenon through AI enabled me to have a deeper understanding of methodological and ethical issues while working with vulnerable and marginalised groups and to uncover a narrative that is richer and more comprehensive than I could have ever imagined. Now, my greatest hope is that the readers of my study find it enlightening, meaningful and useful.

Summary

This chapter has described the AI approach and outlined the process of recruitment, consent, data collection and analysis. This section also elaborates my learnings and the effect of my lived experiences as a researcher and the context I worked with these women. The next chapter presents the initial introduction to the findings from interviews and focus group discussions.

Chapter 4: Introduction to the findings

Introduction

This chapter introduces the findings of the study and provides the socio-demographic characteristics of the participants and stories of women's experiences who they had undergone FGM as children or adults and its effect on their health.

The findings are presented in the following chapters that represent themes in line with the '4Ds' cycle of Appreciative Inquiry as outlined below with an additional theme concerning women's stories of undergoing FGM as the crosscutting theme that linked to all components of the 4Ds cycle. The direction of arrows in Figure 5 illustrates the relationship between themes and their relevant sub-themes. (Figure 5)

The key themes are:

- My FGM story
- Appreciating and discovering the positives in maternity care (Discovering)
- Desiring the best in maternity services (Dreaming)
- Planning together for improved maternity services (Designing)
- Improving and sustaining (Developing/Deploying)

Figure 5: Emerged themes and sub-themes

The themes based upon the 4Ds of AI contain data that were coded into sub-themes further revealing women's needs and suggested improvements for maternity care. These are listed below in Table 2.

Table 2: Themes and sub-themes based on the stages of Appreciative Inquiry

Chapter 5: Appreciating and discovering the positives in maternity care (Discovering)
5.1 The availability and safety of maternity services
5.2 Deserving dignified care
5.3 Receiving the support of families and friends
5.4 Accessing competent and appropriate services
5.5 Promoting normal labour and birth options
Chapter 6: Desiring the best in maternity services (Dreaming)
6.1 Adjusting maternity services to the needs of the individual woman 6.1.1 Providing support services post de-infibulation 6.1.2 Maternity providers with a similar cultural background'; a dream 6.1.3 Seeing each birth as an individual event
6.2 Involving women in their own care 6.2.1 Facilitating informed choice 6.2.2 Shared decision-making
6.3 Accessing fair and equal maternity care 6.3.1 Treating women as equal and special 6.3.2 Receiving language and interpreting services 6.3.3 Providing privacy and respecting confidentiality
Chapter 7: Planning together for improved maternity services (Designing)
7.1 Promoting cultural safety practices through education
7.2 Implementing midwifery continuity of care
7.3 Improving communication and emotional support
Chapter 8 : Improving and sustaining maternity services (Developing/Deploying)
8.1 Mobilising and enabling communities

8.1.1 Advocating, educating, campaigning 8.1.2 Involving men 8.1.3 Empowerment of women
8.2 Strengthening maternity care systems
8.3 Increasing government support

4.1 Socio-demographic characteristics of the participants

The 23 women were from six different countries, that is, Sudan (n=9), Somalia (n=6), Sierra Leone (n=3), Egypt (n=2), Indonesia (n=2), and Ethiopia (n=1). The majority of women (n=21) had undergone FGM when they were 0-10 years old with two women undergoing FGM between the ages of 15-19 years. Most of the women came to Australia as refugees; except for four who came through spousal visas or employment visas. English was the second language for all women.

All the women were married and were aged 26-46 years, with a mean age of 38 years old. They had lived in Australia from 8-25 years with an average of 14 years. All of them had at least one live birth between 2005-2017 in Australia, with most giving birth after 2010 (n=18). One woman was pregnant at the time of the interview.

About half of the women (n=12) had a tertiary level of education; nine had been educated to secondary education level and two to primary education level. The majority of women were from a Muslim background (n=19) and four were practising Christians. More than half of the women were employed outside of the home (n=13).

Table 3 presents the demographic characteristics of women. Ranges have been provided for age, age of FGM and years in Australia to protect anonymity and confidentiality. All names are pseudonyms.

Table 3: Demographic Information

Study code	Age	Age undergone FGM	Country of origin	Date of last birth in Australia	Education level	First language	Employment status	#Children born in Australia	# Live birth	Years lived in Australia
W10	30-35	5-10	Somali	2012	Secondary	Somali	Employed	1	1	20-25
W11	30-35	5-10	Somali	2005	Primary	Somali	Housewife	5	5	20-25
W12	30-35	1-5	Somali	2013	Secondary	Somali	Employed	1	1	10-15
W13	30-35	1-5	Somali	2010	Secondary	Somali	Employed	3	3	20-25
W14	40-45	<1	Indonesia	2004	Tertiary	Indonesian	Employed	3	3	15-20
W15	40-45	10-15	Sierra Leone	2013	Tertiary	Creole/Temne	Employed	2	3	10-15
W16	25-30	5-10	Sierra Leone	2016	Tertiary	Temne	Employed	2	2	15-20
W17	30-35	1-5	Sudan	2013	Secondary	Arabic	Employed	3	4	10-15
W18	35-40	5-10	Sudan	2009	Tertiary	Arabic	Employed	2	2	15-20
W19	25-30	15-20	Sierra Leone	2017	Secondary	Creole/Temne	Housewife	2	2	5-10
W1	40-45	1-5	Sudan	2011	Secondary	Arabic	Housewife	3	5	10-15
W20	40-45	<1	Sudan	2006	Tertiary	Arabic	Employed	1	1	10-15
W21	35-40	1-5	Sudan	2015	Tertiary	Arabic	Housewife	3	5	5-10

Study code	Age	Age undergone FGM	Country of origin	Date of last birth in Australia	Education level	First language	Employment status	#Children born in Australia	# Live birth	Years lived in Australia
W22	35-40	5-10	Sudan	2017	Tertiary	Arabic	Housewife	4	5	5-10
W23	40-45	1-5	Somali	2009	Secondary	Somali	Housewife	5	5	15-20
W2	35-40	1-5	Ethiopia	2011	Secondary	Arabic	Employed	3	3	15-20
W3	25-30	5-10	Sudan	2016	Tertiary	Arabic	Housewife	2	2	10-15
W4	40-45	1-5	Sudan	2012	Secondary	Arabic	Housewife	2	5	10-15
W5	30-35	5-10	Egypt	2016	Tertiary	Arabic	Employed	3	3	5-10
W6	35-40	1-5	Egypt	2015	Tertiary	Arabic	Employed	3	3	5-10
W7	30-35	1-5	Sudan	2014	Tertiary	Arabic	Housewife	1	1	5-10
W8	35-40	<1	Indonesia	2012	Tertiary	Bahasa	Housewife	2	3	5-10
W9	40-45	1-5	Somali	2007	Primary	Somali	Housewife	1	1	10-15

4.2 My story of FGM

This theme provides the background to the women's experiences of FGM to assist with understanding the long-term effects of such trauma on their physical and mental health and their experience of maternity services in Australia. The process of AI enabled women to open up and share their experiences including their stories of having undergone FGM. These intensely personal stories of pain and suffering have the potential to contribute to a positive change in ending this practice and improving maternity care. Furthermore, they raise questions regarding possible future action that needs to be undertaken to support these women. Although most of the stories in my thesis provide deeper insight into this issue, readers may find some of them traumatic to read.

The focus of this study was on women's experiences of maternity services in Australia and there were no direct, research questions inviting women to recall their experience of undergoing FGM. However, many women felt a strong need to express themselves and provide full accounts of their experiences. The physical and emotional repercussions of FGM were intrinsically bound with how women approached and experienced pregnancy and birth in Australia. The very experience of reflecting on experiences of pregnancy, labour and birth, and maternity care drew out traumatic memories of FGM.

The stories revealed socio-cultural factors and gender norms that were associated with FGM. While each woman's story had its own unique personal and cultural elements, or collective patterns of trauma, pain, complications, anger regarding victimisation and gender-based violence were common across all women's accounts. It was evident from women's accounts that they could be living with Post Traumatic Stress Disorder (PTSD) which may never have been properly investigated or diagnosed and may have long-term effects on their life.

Most women recalled the age at which they underwent FGM and the details of how traumatic it was. There were several cases of women who described having been cut multiple times. This was the result of perceptions that the procedure had not been undertaken “properly”. This is illustrated in the story below.

> *The first time I was so young, maybe three or four years old and because they did it for my elder sisters, they did it for me too; you know, it was cheaper if they did it as a group. That's why neighbours and relatives usually planned together. I still remember the long queue of small girls who were very stressed while waiting. It was like waiting for a butcher to cut a piece of your body. I remember afterward they closed our legs together and wrapped it with a robe because they think it will be closed better and they make sure nothing is left opened. When we wanted to go to the toilet they unwrapped it but you know to open our legs and urinate was like torture, so most of the time I hold on as much as I could; it was so painful. After a few days again the lady came and checked all of us and told my mum that I am not closed properly and had to cut me again... After one year or two years, they re-did it. And again, they said it is not closed it must be closed all the way down but mine was a bit open compared to the other girls and they did it for the third time. Oh my God, it was just a little bit open not that much but they forced my mother to re-do it. My mother was so worried because she thought if it is not closed as other girls no one would marry me. I remember even after the third time my mother was still worried about my marriage. But, my dad said, “I won't let them do it for the fourth time, that's too much”. That was my mum who was pushing that “no we should do it properly”. The third time I was eight years old and at primary school. I still remember I was so worried that other kids might bully me if they find I am still open [uncircumcised], you know, girls used to talk about that stuff. (W23)*

Women reported that, due to stigma and social pressure, it was challenging for a girl to remain uncircumcised, or not undergo FGM. In one case a woman described choosing to be infibulated after she was married.

> *I was not circumcised when I was a child back at home. Because we were in a village and were so poor my parents had no money and couldn't afford to cut me. That was a big stigma because, everyone asked you about it. So, no one wanted to marry me and finally, I got married to a guy who was already married and much older than me. I mean, you would lose all the opportunities because your culture tells people what to do or not to do. I was always stigmatised and blamed for not being circumcised. So as soon as I got married, I went and got cut myself and I do not regret it because I wanted to be part of my society and that's how you can be. (W19)*

Women explained that their parents wanted to make sure that their daughters had the same type of FGM as others to ensure that they were the same as other girls and hence, part of the community and known to be following their culture. One woman said:

> *My mother told my dad that we should do Sunna [type 1] but my dad said no we should do 'Ferawni' (type 3). Because my auntie wanted type three on her daughters, my father said why shouldn't she have it too. My father wanted me to be the same as other girls and undergo the same process, he didn't want me to do the easy one (type1). (W12)*

Women talked about short and long-term complications following FGM, such as bleeding, urination problems, and painful sex and birth complications:

> *Oh my God I had so much pain at the time they cut me, you know, it is continuous pain throughout my life. I had a bad pain and a lot of bleeding and then after that, a problem with urination because they closed it all the way down just left a small hole for urination. I couldn't walk well for a long time. When I married, oh that was horrible. And then when my baby was born, I had lots of complications. (W9)*

Some women told of how they had been cut just before they left their country, as their family were aware that the practice was not allowed in countries, such as Australia, or that they may not be able to find a person to perform it outside of their home countries. For example, two women told of how they had been undergone FGM in refugee camps before their departure to Australia:

> *… my Mum heard that the practice was not allowed [in Australia]. She called some people at the refugee camp two weeks before we departed for Australia to perform circumcision on both of my two and three-year-old sisters. (W10)*
>
> *It was painful. There was a whole line of girls in the refugee camp who all wanted to do this before they go overseas as they knew it was illegal elsewhere. They pulled our knees open and tightened them to something on two sides and a lady sat between our legs and because she was doing a group of girls she did not even change the razor blade. I did not want to open my knees to two sides and they burnt me with a candle which they used to put the blade in the right place, to see the cutting area clearly. After they cut me and sewed me all the way down, I couldn't pee at all for a long time. I had to lay sidewise and pee because there were ropes tight around my legs all the way down and we were not allowed to walk. It was really a bad experience and I will always remember it. (W13)*

Summary

This chapter provided a brief outline on the overall findings, demographic information and women's experiences undergoing FGM. Women described traumatic memories of undergoing FGM that have greatly impacted upon their lives

The following four chapters now report on the findings of the study according to the four stages of Appreciative Inquiry.

Chapter 5: Appreciating and discovering the positives in maternity care (Discovering)

Introduction

The discovery chapter is concentrated on women's description of events during their maternity care, and the strategies or approaches that women perceived to be useful, or inappropriate in Australia. For the most part, women were appreciative of, and satisfied with, the maternity care they received. This included being provided with respectful care, a feeling of having a safe service, receiving the required information, having access to skilled health care providers, and being able to have advance care planning and family support. Women frequently reported that "Maternity services are really good in Australia compared to where we came from".

The themes in Table 4 will be described in this section, and are illustrated with quotes from women.

Table 4: Appreciating the positives in maternity care (Discovering)

5.1 The availability and safety of maternity services
5.2 Deserving dignified care
5.3 Receiving the support of families and friends
5.4 Accessing competent and appropriate services
5.5 Promoting normal labour and birth options

5.1 The availability of safe maternity services

Women felt that overall the maternity services are safe in Australia. They appreciated having access to a care plan before their labour and birth with appropriate referral system in place. This helped them to feel confident and not at risk of adverse health outcomes due to a lack of resources or skilled staff as illustrated below:

> *They [the maternity providers] were aware of how to deal with me and I felt supported and assured that somebody knew what I was going through so, you know. (W13)*

Many women considered themselves fortunate to be in Australia where higher quality services were available near them compared to their home countries as one woman said here:

> *[The] availability of the services compared to in my country is amazing. And some hospitals also refer their high-risk cases to other hospitals for the operation but I was happy that my hospital had all the facilities so I did not have to go somewhere else. (W20)*

Some women also talked about access to advanced technology, medical equipment, screening and follow-up care in the Australian health system, explaining:

> *The good thing was always feeling safe, knowing there are all the facilities, medicines and machines and skills you might need available within the hospital. I really felt relaxed in both my deliveries. My hospital was well organised and they checked me regularly and looked after my baby. Overall, pregnancy was a happy experience for me and I knew they would help me straightaway compared to my country where nothing is available. (W18)*

> *They give you the right medication and you have access to all the services you need. Their medical support is excellent compared to my country. I mean it was good to have access to all facilities and have a safe birth with no complications or anything going bad. (W19)*

Most women who received publicly funded maternity services expressed their gratitude, for example:

> *All the resources are available and if anything goes wrong you have access to the care you need such as emergency preparedness. Also the fact that check-ups are free for women is amazing. (W16)*

Women also emphasised the availability of post-partum support and home visiting and those who had access to such services enjoyed receiving this, as highlighted here:

> *They [the midwives] explain everything to women and then after the baby is born, they come every week and if needed, twice a week. They need to check the baby and check the cut area to see if it is healing properly and that there is no infection. (W10)*
>
> *The service I really enjoyed was after care you know when you leave hospital someone comes and visits you. That is really good especially when I had my first kid and it was a time my parents were not with me. (W16)*

Many women who recognised the benefit of post-partum support wanted it to go on for longer, and more frequently after birth. They said:

> *They should have someone to support us. They sent a midwife after birth but only one or two times, that's it. At least they should have continued for a couple of months. You know, until you get comfortable. (W2)*
>
> *I would like nurses to come and follow up after birth at home because we might get different problems from other women…and check everything and ensure my baby and I are alright. At least they should keep us longer in the hospital or provide three weeks follow up after birth. (W9)*

Another woman also acknowledged that she felt safe because the maternity care system encouraged women to attend regular antenatal visits and postnatal follow up. She said:

> *The fact that maternity check-ups are very regular and effective is great despite waiting times. Not everything is perfect but still, it is really good that the services are available to you and it ensures you are in a safe place. (W15)*

Women felt comfortable and reassured when maternity care providers interact with them and let them know they had experience in caring for women with FGM.

> *I really appreciated my midwife referring me to a male doctor with expertise. He told me, "Don't worry, I have seen many women with FGM". He ensured me at the very beginning that he had a very good experience with women with FGM and that it was easy for him to deal with it. At that time someone told me he was very experienced with FGM. It made me happy, calm and relaxed knowing that there was someone who could take care of my FGM and that I was in safe hands. The doctor was Middle Eastern' [similar to my culture]. (W1)*

In contrast, several women expressed a sense of fear and insecurity about the maternity care providers if they perceived they were not knowledgeable about FGM. Seven women chose a private obstetrician as this made them feel safer, for example:

> *When I had my second baby I knew by then that the staff in the hospital don't know anything about FGM so I went to a private doctor in advance and they open my circumcision properly and after that I had all normal births with a bit of cut [episiotomy] in my fourth [birth]. (W23)*

Women believed that if a maternity care provider is inexperienced, they might mismanage FGM and cause more complications and that would make them feel unsafe.

> *The medical staff need to understand this issue [FGM] and be knowledgeable about it and if they don't have hands on experience and skills please do not touch us and make our situation worse. You need to feel safe knowing that they get training before coming to women with FGM. (W23)*

This section provided an overview of how the availability of individualised health services by competent health workforces provide women with a sense of safety and trust on the health system.

5.2 Deserving dignified care

Women felt they deserved respectful, non-judgmental and dignified care during pregnancy and childbirth; their comments about their experience of care in this respect were both appreciative and critical. In general, women felt happy about the way they had been treated as individuals. Their comments often reflected the fact that they had been subjected to disrespectful care before coming to Australia, as the examples below show:

> *The services are good, people are nice and respectful, and believe me if you want our respect you should respect us first. (W11)*

> *Their [maternity care providers'] general behaviour was really good, the way they talk was good, they do not shout'. (W6)*

When women received respectful care, it made them feel calm, reduced their anxiety and reassured them of their safety, for example:

> *The staff really reassure you and they are really good. They reduce your stress by asking how you are: "How is your baby? How was your sleep?" You know that they are reassuring you that there is nothing to worry about. These types of communication are very important to reduce postnatal distress. (W15)*

Most women indicated that, in their experience, the relationship that midwives had with them contributed to them feeling respected and calm, as this woman said:

> *My midwife was so good; she was old [experienced] and so close to me all the time. I still remember her, I felt she was like my mum or my older sister. She took me to the shower and helped me to take a shower, and every couple of minutes, she came to me and just talked to me like a family [member]. She was the only person who told me you will be OK. She gave me that sense of relaxation when I was with her. (W18)*

A few women were satisfied with the way their maternity care provider had respected their privacy, for example:

> *I guess they are really good with privacy and that sort of stuff. For example, when the doctor comes into a public room, they close everything and asked us to cover beforehand. Except for my first birth, for the rest I had a private*

> *room. (W21)*

The provision of dignified care was not universal, however, and some women felt they had been looked down upon, abandoned or ignored by maternity care providers. This woman articulated this here:

> *Sometime you go to see the doctor, they think we are not important, they talk to us like a machine for two minutes and then ask you to go out. I do remember once they checked me and as I took off my shoes when I lay on the bed, I had to put them on after examination but she said go out and do it. They just don't respect you and look at us as a business not a human. (W10)*

Some of the women believed that the reactions of maternity care providers could be a product of the personal problems of the providers themselves, as explained in these quotes:

> *Some of them [maternity care providers] come to work with their private problems. They bring all the anger to us as a patient. You can even see in their face how annoyed they are. Some of them even don't look at you while they do their job, for example taking your temperature just not looking or talking to you and I keep asking them how is my temperature, again. How is my temperature? And then she pretended she did not hear me and said, "Pardon?" And again, I repeat and she says, "Oh yeah it's ok". And that's all the sort of communication which makes you upset. (W18)*

> *You know when the nurses change the shift and sometimes you get the kind nurse and sometimes you get one of those who had a bad day and wanted to reflect all the burden and anger on patients and we as clients feel they are sick of us but in reality, they don't even know us ... there were also those who cut you off before you finish your question or concerns. They kind of make you feel this does not matter to them or does not make sense to them, that you are not important, you know; this makes you feel small. But the majority are really nice. (W13)*

Some women reported feeling disheartened and anxious by the comments and reactions made by maternity care providers about their FGM appearance. For example:

> *When she [the maternity care provider] looked at me she was shouting "Oh my God, you are burnt there [her vulva.]" Then I said, "No that's not burn; my parents make me like this when I was young". (W9)*
>
> *They are not experienced and don't tell you blah blah blah [giving information] about this [pointing to her vulva/FGM]. By reacting shocked, they make you a lot more worried and make you think a lot - what is wrong down there. (FGD1)*

Another woman described her disappointment at the disrespectful behaviour of maternity care providers when she refused to be treated by a male doctor. She said:

> *I was waiting for a female doctor the whole day. They didn't tell me anything till the end of the day when they said, "Oh we don't have female doctor we just have male" ... I got into the room and this male doctor looked at me like angrily and then said, "Why do you think you are special? If you don't want me, walk out [go away]. You are not special. I am not a woman but I am a doctor". So, I was so disappointed and I just said I want a female that's it and got out of the room... I always used to see a female and culturally I don't like to be touched by male doctor unless there is no option. This doctor was attacking me somehow about my choice but I didn't react and just said, "That's my choice and preference; that's it". (W23)*

Some women experienced feelings of isolation and loneliness in the maternity care system because they felt they had not received dignified care due to their FGM, for example:

> *You feel lonely and different to other people. And you feel stressed not knowing what they are going to do with you as someone who is different, you know, with FGM. (W23)*
>
> *The nurses leave you alone because they think we have the experience with*

> *FGM and we can deal with it and expect you to do everything by yourself. They consider us like other normal women rather than giving us extra services or attention. (W5)*

The women felt that the maternity care providers were judgmental and disrespectful of their culture and ethnicity. This could be expressed as ignorance and, at times, discriminatory behaviour:

> *I didn't know much about the health system here and also, I had never been at a health facility before [being pregnant]. When I got there, I felt everyone acted like I am dangerous and sick and they didn't want to touch me sometimes because they were thinking I have dangerous diseases. (W19)*

Such negative comments and behaviour discouraged some women from continuing with their follow up visits. Many of the comments were unrelated to being affected by FGM but highlighted broader issues of disrespect. For instance, these women said:

> *They always gave me negative comments in a very rude way: "Why you put on lots of weight, why are you eating a lot?" This made me so worried, I tried even to avoid food for a while. And I was not eating that much. I was under medication for my asthma and they knew that but were still blaming me… I hated to go for my visits, it made me stressed. (W20)*
>
> *One of them [a midwife] asked students to do everything and just looked at me, like annoyed. One of them said, "Why you have this baby to just make our life and your life hard?" You see with such comments I felt so unsafe and I was thinking, "Is she able to deliver my baby safely [if I'm such a hard case]". (W10)*

Women described times when they felt that their privacy had been violated and this made them feel undignified. They said they felt uncomfortable and embarrassed when there were a number of maternity care providers in the room while they were naked, as articulated here:

> *They [maternity care providers] were like shocked [by the FGM] and were asking, "What happened to you? How can your husband sleep with you?" And then they called so many people to look at me while I was embarrassed and felt so unsafe with low privacy. (W10)*

> *You know I don't like when I was naked and all these doctors surrounding me and looking at my body and violating my privacy. Also, other patients were near my bedside. (W13)*

Many of the women felt too vulnerable to ask maternity care providers not to let others come and observe their FGM, for example:

> *They sometimes got permission to call others but it depended on the urgency and situation I was in. Sometimes I didn't even know why all these doctors and students are around and looking surprised at me [my vulva]. It is out of your hand [control] even to say something; you feel so vulnerable and weak because you are in need to get rid of that situation and pain. I am not saying I was unhappy, I just felt embarrassed and uncomfortable because everybody was looking between my legs and I felt something is wrong with me. (W13)*

One woman said she agreed to be viewed by other people against her wishes and she felt disempowered and therefore unable to refuse:

> *They [maternity care providers] said, "A lot of people are coming to look at you; are you OK [with that]?" I was so tired and just said OK while I was not really OK. (W9)*

Women felt that maternity care providers were often in a rush and sometimes aggressive and that this prevented effective communication and dignified or respectful care. Some women's accounts may not specifically relate to FGM, however the treatment of providers influenced their overall experiences during maternity care. These women explained this as:

> *When I lay down, no one told me to take off my clothes and pants to make me ready. They should have told me at the beginning because no one knows when the baby will come and I was in pain and therefore I did not think of anything. But when all of a sudden my waters broke, they handle me like a piece of meat and aggressively changed my clothes. Choo, choo, choo [makes a noise to indicate being rushed aggressively] …Nobody explained to me what is going on. (W2)*
>
> *'Then she entered her hand into my vagina very, very hard and aggressive. She put something inside to break the water very hard, not with patience or slowly, slowly. (W6)*
>
> *Here in [Australia] the doctors are like, write, write, tick, tick and then go, go. They look at you as a number not as a human who has come to talk to you. At the end of the day, they say, "OK, 100 women visited the doctor". It is just rubbish if you didn't talk to us even for 5 seconds. (FGD3)*

Most women did not know how to complain when they felt that they had been treated disrespectfully or in an undignified way. They felt too vulnerable to say anything, for example:

> *When we talk among ourselves within the community, I realised everyone has a bad story from the hospital, like stories of inexperienced doctors or racism. We all don't know how to complain even when something happens to us, so we don't complain. Maybe because we feel unsafe to complain or maybe some of us don't know we can complain. I didn't know, for example, that I could complain at the time they missed membranes in my uterus and I went through another surgery unnecessarily. Later, I did not complain because I thought it might be a headache for my next birth and nothing will be reversed. Also I had already suffered. (W21)*

This section provided a summary of examples of women's views on dignifying maternity care that may or may not be related to their FGM but they believed it would have influenced their overall experiences.

5.3 Receiving the support of families and friends

Women highly regarded having the support of family and friends during their maternity care. Involving families in decision-making was key, especially when the women were in a position where they felt they were not able to make decisions, such as during an emergency or de-infibulation. Being with the family was considered an important form of emotional and cultural support and, in many cases, women felt comfortable that their family served as interpreters during maternity care, despite this is not being a practice that the health system supported, for example:

> *It was good I had always my friend and my husband beside me. They were supportive. They [maternity care providers] asked me if I'd like an interpreter. I said no because my husband was there… It was also great you feel you are beside your family and that's a big emotional support. (W17)*

Most women believed in the importance of involving family members in their care so that they could learn about physical changes in relation to FGM and understand the need to support procedures such as de-infibulation. They made comments like:

> *I believe that it's very important for families to get involved in maternity care and talk about issues, such as de-infibulation. Simply when doctors and midwives talk to us, they also need to convince our family. They [family] need to know all the steps we go through to be re-opened otherwise that's a dilemma for women because they need to stand against the culture alone. (W13)*

> *The most important thing which I like here is they always involve your husband in all steps of your pregnancy and birth, which in our culture doesn't happen. It is really important because men consider pregnancy as nothing but after my husband experienced all the steps with me, he is more*

> *respectful and supportive. For example, in my second pregnancy he helped me with household work and he took care of our kids a lot. (W19)*

In contrast, many of the women felt vulnerable, isolated and lonely when their partner, family and friends were unable to care and support them during interactions with maternity services. A few mentioned that, despite the fact that they had their family with them in the hospital, they were not allowed to be in the room with them, for instance:

> *Especially for the husband, they should make sure he can be there 100%. For example, when I open my eyes the first thing, I looked for was my husband and he was not around. I couldn't talk and I was just turning my head around to find him because he was what I needed the most at that time. (FGD2)*

Women considered childcare to be a significant barrier to having family support at the hospital, describing situations where their husband or a close relative had to stay at home and look after their children. One woman said

> *I left my son for two weeks with my mum and went to the hospital. I feel lucky my mum was around to look after my son otherwise I don't know what to do. (W10)*

One woman described how she had to travel back to her country of origin with her children so that her family back home could take care of her children while she was giving birth. This had unintended consequences for her as she explains:

> *My first one born in Australia naturally. I was really stupid because I went for my second one to Indonesia and ended up with a [routine, elective] caesar. I had no idea that would happen. I was afraid because I had nobody here [in Australia] to take care of my first one. (W14)*

In some cases, women stated that they had to rely on assistance from community members after they gave birth, as they had no access to family support. This highlighted the social isolation that many women experienced, for example:

> *My community also sometimes cooked food for me, which was a great support, as my husband does not know how to cook well. (W9)*
>
> *At that time, our community was so small and I just know two or three families from my community. But all of them were busy and I couldn't ask for help. (W17)*

Women had mixed feelings about their short stay in hospital. A few appreciated the fact that they were encouraged to return to their normal routine life after birth, as this woman explained:

> *In Australia, I loved the way the next day you don't have to be in bed; you can stand up and do your own household work and take care of your children, but in my country they force you to lay down for one or two months, which is awful. (W21)*

Most women, however, felt that they needed a longer stay in hospital especially as they had little family support at home for them in the early postnatal period. These women said:

> *In my culture, when you deliver, they (family) help you and support you to take care of your baby, especially for the first baby, we don't walk or do extra jobs, but here they didn't even wait for a few hours for me to recover. They asked me to go home and I had to do everything and had no one to help me despite the fact I was tired and dizzy and had a big tear due to my FGM. (W9)*
>
> *I really wanted to stay longer in the hospital because I wanted to make sure everything was ok. Secondly, that is the only time I could rest and relax and my body recover. But as soon as I get home I need to go to the kitchen and*

> *do all household works and no more time for recovery, especially when you have four or five more kids at home and no family to support you. (W22)*

Some of the women were concerned about asking their husband for support, as it required him to take time out of his job and not culturally common. They said:

> *He [my husband] helped me a lot and cared for our baby. He took almost five months off from work to stay at home and help me. (W9)*

> *They do classes or workshops [referring to antenatal education during pregnancy] but I didn't go because it is two days and they need pairs [husband and wife]; my husband was working and I was not driving. (W7)*

Most women described that a lack of partner involvement in was often the result of cultural expectations and gendered roles, for example:

> *If I say to my husband to cook or look after the kids, he would tell me, "Oh now you become like a Westerner now! (FGD3)*

This lack of involvement could be re-enforced by the attitudes and practices of maternity care providers, as the following women described:

> *My husband came with me for a few visits but the midwife was always talking to me and excluding him, so he got bored and did not continue to come. (FGD3)*

> *The way the doctor and midwife communicate with men is as if he's not someone who is part of the process, someone who is an outsider; most communication is for us. They should tell men what they need to do to make it better for us. (FGD2)*

Sometimes, women noted that maternity care providers had told men that it was not necessary to attend the antenatal visits, and so men chose not to be present, for example:

> *My husband was just in the first session with me and then they [the midwife] said, "You don't need to be there always" and he didn't come to visits with*

> *me again. (FGD3)*

Some of the women felt that maternity care providers could play a more active role in encouraging men to be more involved in supporting women saying:

> *Maybe if someone else like our doctor and midwives ask them [men] to help us during pregnancy it is more effective than we telling them. (FGD3)*

The current section explained women's accounts about socio-cultural norms in relation to the involvement of family, specifically men, in the decision-making.

5.4 Accessing competent and appropriate services

In both the interviews and group discussions, women were asked to describe what they liked about their maternity care and what they would consider an ideal maternity service for women with FGM. Overall, they wanted maternity care providers who are competent, responsive and attentive. They expected their maternity care providers to have an appropriate level of knowledge about FGM, possess effective communication skills, be sensitive to their cultural needs and involve women in their care.

A few women thought that, despite FGM being a rare event in the experience of Australian maternity care providers, they should know how to deal with it, or at least, know what sort of questions to ask in order to learn from women. This woman said:

> *… it is not like that the doctors and midwives in Australia come across a circumcised woman every day, you know. And I don't blame them if they are surprised or ask you millions of questions. (W13)*

Most of the women appreciated maternity care providers who were helpful, sensitive and responsive to their needs, especially when they had no family and relatives around to support them. They made comments like:

> *The way they helped me was very good, quick and efficient. For example,*

> *immediately on arrival the nurse was there to help me and she took me to the ward and prepared me. What stayed with me was their quick actions and the nurse was very caring and kind. (W18)*
>
> *Friendly staff who talked to us, responded to our needs clearly and correctly…When you asked them questions, they allocated time and talked to you and explained to you until they made sure you understood everything you needed to know. (W14)*

Women said they were impressed by the way maternity care providers made them feel cared for, particularly when they followed up to make sure women did not miss their appointments. These women explained:

> *I always forgot my appointments and my midwife called me and reminded me to come to visit them and if I don't reply they come to my house or re-scheduled it for me. The date which I was supposed to have my baby I had no pain but they [midwife] called me and told me if I had no pain till the next day I should go and check with them because I was already due. (W22)*
>
> *It is more relaxed when the doctors and midwives give you time and talk to you with patience, and are nice and calm. They always check so you don't miss your appointment and you love to go to such environment when you feel everyone cares for you. (FGD3)*

The women believed that developing trust with a maternity care provider was directly associated with the provider's competence. Some women felt anxious and lost their confidence in maternity care providers' competency when they saw that their care providers were surprised or shocked when they encountered the woman's FGM. One woman in a focus group said:

> *If these midwives and doctors know where to cut (de-infibulation), how to cut and when to cut it will be so helpful for us and for them because we will not have a problem and they will be relaxed and confident in what they do. Now as soon as they see us, they are shaking … Oh my God. They can get*

> *advice from doctors and midwives who worked in our country and have real experience of treatment of women with FGM. (FGD3)*

Women expressed their disappointment when they did not receive the level of care they expected, for example:

> *You know what I heard during my training on FGM [community-based workshop] was that nurses and doctors know everything about FGM but in reality, when I had my baby, I realised they don't know anything. They should advance their skills and knowledge. (W12)*
>
> *When my baby was about to come out, seven doctors and midwives were coming to look at me and no one had an idea what to do, so they cut me everywhere. We worry because we think they may not know how to open us. (W19)*

Some women also believed that maternity care providers might put them at risk by delaying clinical decisions due to a lack of skills and confidence in relation to FGM. For example:

> *They didn't even break my waters. They were just sitting down there and waiting while I was in pain. They just came in and out and did not even talk to me about what is going to happen and at the end one came with needle to [put me to] sleep me for an operation. (W19)*
>
> *They need to be quick in their decision for women. They leave us to suffer a lot and at the end they send us for caesarean. Which should be done at the beginning but they put us and our baby at risk by keeping us waiting and waiting. (W6)*

Women's accounts highlighted the importance of clinical skills in developing trust and improving compliance with their care.

5.5 Promoting normal labour and birth options

Women recognised and valued their natural capability to experience birth as a normal process without unnecessary intervention. Some perceived that their FGM was not necessarily a barrier to undergoing a normal labour and birth and questioned interventions such as caesarean section. Several women stated, '*we had our baby normally and easier in our country; why not here'*. Others said:

> *I wish to go through all the natural experiences rather than surgery and pain because the risks of aftermath when you have a caesar are a lot. (W13)*
>
> *People keep telling me that we all gave birth naturally back home and you can do it, don't go in before your pains start. (W12)*

Women believed that maternity services should provide more options for de-infibulation during pregnancy in order to optimise their potential to have a normal birth:

> *I feel so sorry for women with FGM type 3 because they have no option for normal delivery. Most of my friends they had a caesar because of FGM. I want more services and options available to those women, like they can open them before while they are pregnant and can give them a chance to have a normal delivery if it is possible. I don't know. (W5)*

One woman stated that, despite her insistence that she wanted to be de-infibulated during pregnancy in order to have a vaginal birth, the maternity care provider refused:

> *I requested them to open me during pregnancy rather than leave everything to the last minutes because I wanted a normal birth but they said, "Oh it is too late, we cannot do anything now. Just wait". I think I was seven months [pregnant] and they told me, "It is too late already. We'll see what happens when you have the baby". So, I was convinced it was too late. (W23)*

However, overall though, many women felt happy that the Australian maternity care system had given them the courage to have a normal birth, when they doubted their ability to have one:

> *I was shocked and he [the doctor]) said your baby may not come out; it will*

> *be too hard for you to have a normal delivery [without de-infibulation]. When they showed me the picture and the way they were going to cut me I was so scared. I said, "Oh my God, rather than get that 'X' tear on my body I would prefer a Caesar [with laughter]. But to be honest I am happy they pushed me and I had a normal birth and I enjoyed it despite the pain. I am really thankful for their support. (W9)*

Women appreciated the fact that in Australia, the maternity care system supports normal birth. Some women believed Australian maternity care providers are encouraging and valuing of normal labour and birth, and this was appreciated. They felt they had been given enough time and opportunity to try to have a normal birth with limited medical interventions:

> *In Australia they always try to have a normal delivery, they don't go ripping you off [medical or surgical interventions]. When I got to the hospital for my last one in Australia they were waiting for several hours and kept trying till it [the cervix] is open, helping me try to have my baby normal. (W14)*

Some women, however, perceived that they had undergone unnecessary interventions due to their maternity care provider's lack of skills in the management of FGM. They felt this forced them to undergo a caesarean section, for example:

> *I believe the chance for women to try normal birth depends on who you get, but for me they wanted me to do a caesar because they don't know how to deal with my FGM. (FGD3)*

The perception that having maternity care providers who are not familiar with the management of FGM, leads to a high chance of having a caesarean section was described as stressful, for example:

> *We have a lot of worry in our mind. We don't know what will happen to us if we go to an Australian hospital because no one knows about FGM. We worry because we think they may not know how to open us and that may*

> *cause tearing everywhere in the vagina or they will send us for a caesar. (W9)*

This level of anxiety sometimes meant that women avoided their antenatal care visits, as these women explained:

> *I used to go every two weeks for my check up till they told me I may undergo a caesar due to my FGM and my diabetes. They said the baby is large and your vagina is closed so the baby cannot come out. Then I stopped going to the hospital because I was afraid. Always in my mind I remember our neighbour back home [Somalia]; she had a caesarean and she was screaming and screaming after returning from hospital and as a kid I was so scared. (W12)*

The women's stories frequently revealed that the view of relatives and friends made women feel more anxious and fearful of undergoing a caesarean section. Sometimes, the views of peers led to women delaying their ANC visits at health services or they did not reveal their FGM to caregivers:

> *I remember my mum and everybody telling me, "Oh they want to put gel in to force you to give birth and because you have FGM, everything will be open at once and maybe you die". All my relatives and friends kept calling me and telling me, "Oh we have the experience; don't allow them" and that's why I was hiding all the time - because of them. (W12)*

Women reported feeling scared and worried because of stories and rumours that they had heard about the care of other women with FGM from their community. This added to the stress and anxiety that women felt when accessing services in Australia, for example:

> *She [her friend] was very traumatised during vaginal birth because they couldn't manage her FGM and she had a big tear as a result of bad management of FGM during birth by inexperienced doctors and midwives. I was shocked and so scared of normal birth, wondering if that was going to*

> *happen to me. (W20)*
>
> *Oh my goodness it is always in your mind - how are they going to deal with my FGM. And lots of stories around the community make you more scared and stressed. I'll have my next birth natural but I don't know what to do. I am so scared when I listen to the other women's stories about their circumcision and midwives' and doctors' lack of experience [of FGM]. (FGD3)*

Summary

The 'discovery' process enabled women to share and reflect upon their experiences. Women clearly articulated the positive aspects of their maternity care. Their reflections allowed women to suggest changes that they believed should be made to improve the quality of maternity services for women with FGM. These changes included assuring the availability of competent maternity care providers and appropriate maternity services that enhance safety, dignified care, the promotion of family support and normal birth. Some of these issues are directly related to their FGM, however many are generic issues related to the need for quality maternity services.

The next chapter presents findings of 'Dreaming' phase of AI that provided greater insight into women's experiences and their vision for the future of maternity services for women with FGM.

Chapter 6: Desiring the best in maternity services (Dreaming)

Introduction

This section presents women's visions of how they imagine or dream of the future of Australian maternity services for women with FGM, including how they would wish to be treated within such a system. Women shared their desire for individualised care, involvement in their own care, equal access to services and information, privacy and cultural sensitivity. When considering these issues, several women described feeling that their vision might be limited by their narrow exposure to the Australian maternity care system, as noted by one of the women:

> *You know we are coming from a very poor, under resourced country and so coming to here where everything is available is the best for us. When you ask us, what would you like to be different I might judge from a small window of exposure I have had but if you ask something like this from an Aussie person, they might tell you a lot more. (W21)*

The common themes that arose within this category are illustrated in Table 5.

Table 5: Desiring the best in maternity services (Dreaming)

6.1 Adjusting maternity services to the needs of the individual woman 6.1.1 Providing support services post de-infibulation 6.1.2 Maternity providers with a similar cultural background'; a dream 6.1.3 Seeing each birth as an individual event
6.2 Involving women in their own care 6.2.1 Facilitating informed choice 6.2.2 Shared decision-making
6.3 Accessing fair and equal maternity care 6.3.1 Treating women as equal and special 6.3.2 Receiving language and interpreting services 6.3.3 Providing privacy and respecting confidentiality

6.1 Adjusting health services to the needs of the individual woman

Women revealed a strong need for individualised support services, particularly the provision of emotional support for women post de-infibulation and for those undergoing re-constructive surgery. They also stressed the need for each woman's pregnancy and birth to be seen as an individual event. Three sub-themes emerged under the theme that is elaborated in the next section.

6.1.1 Providing support services post de-infibulation

Many women struggled with the emotional impact of de-infibulation. This was exacerbated by the fact that legislation did not provide the option of re-infibulation. They perceived a reluctance of health staff to consider any form of reconstruction of the vulval or perineal area because of this legislation. Many were unsatisfied with their body image and wished that reconstructive surgery could be part of the services offered to women with FGM. Most of the women believed that their de-infibulation had been done 'badly' as maternity care providers were inexperienced. They desired varying degrees of re-infibulation and used the term 'closed back' when describing reconstructive surgery. Women said they looked 'too open' and their body would be 'in better shape' if they were re-infibulated after birth. These comments capture such feelings:

> *In my country after each birth they again close us as they did for me too. You know it is in better shape if they close it but here, they leave it open. (W21)*
>
> *After they open you during delivery, I wish there is someone who stitches it very very nicely so it doesn't look very open. (FGD1)*

The women wanted to have access to appropriate mental health support about coping with changes in their body after de-infibulation, as these women explained:

> *I want them to look after the area (after de-infibulation) and look after my mentality [mental health] and provide me with counselling because after each birth there are a lot of changes in that area [vulva].*
>
> *If a woman has undergone FGM they need to look after her even after birth and even if there is not any visible harm there is always a change and she needs that emotional support. (W20)*

One woman mentioned that if she were a maternity care provider she would re-infibulate or 'close back' the women with FGM after birth to leave the vulva in 'good shape' saying:

> *I open you and I will close you back. I won't leave you open. I don't mean like Type 3 FGM, just closed in a way so that it is in good shape and not damaging you. (W23)*

Another issue that was regularly described by women was related to their body image and the different ways they have seen themselves after de-infibulation. Most women felt embarrassed and uncomfortable with their body and described their vulva as 'ugly', 'too open', 'not in good shape', 'hanging skins', and 'horrible'. For example:

> *My body is so ugly and open and when I cough, I pass air which is embarrassing. For my second baby I asked the midwife to close me a bit but she said, "It is not the rule". I want them to provide us with services to repair our vagina in a good shape I mean any type of surgery which is needed to make us sexually feel better. You know, in my case sometime I feel embarrassed to show my vagina to someone or have sex with my husband. Because, the way they have done it is not good and make me feel ugly down there. Most women they go back to Africa and close it back because, it is not looking good. (W17)*

As suggested above, there was evidence that a few women did go back to their home country and arranged to be re-infibulated, like this woman:

> *I asked her [maternity care provider] to close. She said, "No we can't do*

> *that in Australia". After that birth I had sex issues and in general I felt so unsatisfied with my body and all those hanging skins around my vagina so I went overseas and closed it by a midwife in my country. You know last time when I [got] closed myself in Sudan it was because it was so big and ugly they left me totally open at least they could have stitched me back to make me look like normal. (W22)*

One woman considered her experience of being de-infibulated as the same as being infibulated in the first place:

> *After each birth they sew me here, here and there [pointing to the vulval area by hand] all different spots which is horrible and I feel that's the ugliest part of my body. The memory of re-opening is as traumatic as the three times I was circumcised in my country. (FGD1)*

After giving birth, women generally wished to see their body the way they were used to seeing it since childhood (infibulated). When they were de-infibulated, they felt uncomfortable about their genitals. Many did not know the difference between normal genitalia and genitalia that had been circumcised, for example:

> *...once they open the cut area [FGM] and leave it open [de-infibulated] we don't feel comfortable as our whole life we were closed and when the area is open, we don't feel sexually it is OK. (W4)*

> *...The problem with us is that we don't know actually what is normal and what is not normal because we were a child and no one told us anything and you cannot say by looking at yourself what is wrong there and we don't have the knowledge. (W7)*

One woman chose to undergo a caesarean section rather than undergo de-infibulation explaining:

> *After birth they gave me the option to either open me or leave it closed but I asked them to leave it closed. I thought if there is no point to reverse the*

> *feeling why I should go for another pain, another wound so I leave it as it is. I went through all the pain and trauma already and hopefully no more. I never had a natural birth because they told me that my FGM the head to come out the space is so little. The risk of having a long labour for baby was too high so they decided to have it by caesarean. (W12)*

Another woman described a more positive experience with de-infibulation but spoke of the need for support to go through the adjustment issues:

> *They kept me open and even they offered me plastic surgery for the area (FGM) and because of them I had an easier birth for my third one because the area was open and I was really happy with their services. Sometimes, we don't accept changes in our mind and we are confused about how to deal with them. We need someone to talk to us as there are lots of issues around our mentality. (W1)*

Many women felt they had been denied sexual pleasure and satisfaction because of FGM and desired a way to reverse that situation. Many felt that re-infibulation or reconstructive surgery would address these issues, for example:

> *In Australia, stitching is not allowed but for us we need to have access to re-constructive surgery. I want that because I am not feeling like a woman now and I am unhappy with my sex life so this is my need that make me happy. (W17)*

Another woman felt under pressure from her husband to undergo re-infibulation although she recognised that she had freedom of choice not to do that. She suggested that, although there might be pressure from some men wanting their wives to be re-infibulated, the most common situation was women wanting the procedure due to a lack of comfort with the look of their genitals following de-infibulation:

> *There are cases of pressure by husbands who want their wives to be closed because they are not used to it but overall it is the women themselves who*

> *want to be closed [re-infibulated] as they think it is not normal to be open'. (W4)*

Some women identified the need for support services involving their partner in order for them to learn about sexual pleasure, whether or not they have been de-infibulated, as this has been such a taboo subject in the past, for example:

> *We wish to enjoy our sex life so we need a really expert person to teach us what to do and also our partner should be well aware of the consequences of FGM, otherwise we are not going to get anything out of it. (W11)*

This section focused on findings related to the psychological aspects of undergoing FGM and the ways in which women perceived their body as normal or not normal. Women believed sexual counselling needs to be part of the maternity care services.

6.1.2 Maternity providers with a similar cultural background'; a dream

Women perceived a maternity care provider to be ideal if they are from a similar cultural background. They believed they feel comfortable with a health providers from an FGM-practising country, whose appearance is similar to women and share a common language. Women believed that a maternity care provider from a similar cultural background would be more skilled in relation to FGM; they also felt that this would make communication easier and should be considered in designing future maternity care, for example:

> *You know it is important to have a midwife from our own culture. I would feel more comfortable to express my needs, talk and share my issues much better to have a doctor from a similar culture. Plus, she might have more skills and experience of FGM'. (W21)*

> *Actually, whenever I saw a nurse with a Hijab [similar cultural background]) I felt more comfortable in asking questions. You know, I felt she might know better about my culture and won't allow men to come into the room. When the other nurses were around, I was always worried that a*

> *man might come in. (FGD2)*

One woman said a maternity care provider from a similar cultural background would have ‘firsthand’ experiences and this would make them feel comfortable about communicating their problems. This might also open up the possibility discussing other issues related to their lives. One woman explained:

> *‘If I am an African, I should be seen by an African doctor or midwife. If they are not from the same country but at least from a similar culture, that still is helpful. You know when you talk to a white midwife about FGM they don’t have first-hand experience and don’t know all of that but with someone from my own background I would engage with them and make them understand about my problem and I would even open up about my other issues which I am facing. No one wants to be with a service provider who can have no idea about your problem’. (W15)*

A few women believed that women may feel even more comfortable with someone who had been through a similar experience of FGM. However, women recognised that this was difficult or maybe impossible. One woman said:

> *‘So, as a provider with the same experience I would make women comfortable and talk to them and let them know I have been through the same thing and I would assure her that everything will be OK and safe for her. Because I would understand the pain it would be easy to make women understand it and make them very very comfortable so they can open up and talk about it’. (W13)*

Some women also described if they were a midwife, they would have a better understanding of women’s pain as they have undergone similar experience and are from same cultural background, as stated here.

> *Here everybody put their fingers in [woman’s vagina] and not even consider how painful and hard it is for us. But a midwife who have same experience*

> *[FGM] would be considerate of that. You know, it is very traumatic because, it gets you back to the days when they cut you and that's why health provider need to first take care of our mental health and relax us by ensuring that they are helping us rather than hurting us. (W20)*

Several women viewed Australian maternity care providers as outsiders to their culture and perceived they could never feel or imagine the pain and trauma they had been through. For example:

> *You [maternity care providers] are like someone from outside. You just learned from the book and have got no idea. When you say I am trained in FGM, actually you don't really know the actual story and the pain behind it because you've never felt it. (W1)*

Women said that they could not share their problems easily with outsiders to their culture. One woman mentioned community-based training on FGM, saying how relaxing and easy it was to trust the facilitator because she was from a similar cultural background. Another woman said:

> *We had a workshop [about FGM] which was really good and everyone was very comfortable and shared their stories because, the lady [facilitator of the workshop] was from the same culture. If there was someone from a different culture, we are not going to say anything or talk openly. Please train more African midwives so we can talk about our problem openly. (W7)*

Since they were invited to 'dream' many women came up with a desirable ideal: they imagined being cared for by a female maternity care provider who had undergone FGM herself:

> *… I would talk with women and let them know this circumcision is a mutual condition that I [as a midwife] had experienced myself and gone through all the pain… This might relax women, knowing that I feel her pain and have experience to help her'. (W23)*

> *[If I was a midwife] every time I meet you, I would talk to you and relax you and ensure you would feel safe and I would tell you I had had the same experience. So, you would know that I feel your pain and am familiar with that situation. (W18)*

This section provided an overview of women's desires regarding cultural needs how it may improve on communication, health literacy, empathy and overall quality of care.

6.1.3 Seeing each birth as an individual event

The women in this study believed that each pregnancy is an individual situation and needs to be treated as such. This meant that maternity care providers should listen to each woman and adjust their care to suit her individual needs, rather than following the same course for every woman. This was a typical quote about individualised care:

> *They need to listen to women as they know their body better. Not everything is going to be according to the recipe in the book. They have to look at each individual pregnancy separately. You know, all those breathing exercises won't work on everyone. (W16)*

The findings from the group discussions also revealed that women believed that maternity providers needed to 'consider every birth as individual birth'. Women said:

> *Even those who have had several births, each birth has its own type and its own experience. Take into consideration the person's background, what sort of support she needs. For example, she might have a language difficulty - all these things need to be taken into account. Because of circumcision most women are in fear. She needs someone who can support her even a little bit. Support will make a big difference for her. (FGD1)*

Women believed they knew their body better than anyone else but felt that maternity providers did not pay attention to their individual experiences, for example:

> *Women know their body and their pregnancy better than anyone else so they should listen to us. If the midwife has the knowledge, we have the experience. Please listen to us also. (W22)*
>
> *I went to the hospital but they told me to go back home: "You are not in labour". But I knew I was in labour. I came back and I had a very fast labour and I had other complications. They never took into consideration I was circumcised. (FGD1)*

Those women who had had positive experiences of receiving individualised care, tailored to their needs, were able to draw on those experiences in articulating what could be possible for all women with FGM, for instance:

> *The midwife really was good. She taught me a lot of things during pregnancy and two weeks after my birth. It was really useful for me as someone who was having first baby. That was something I really really liked. I wanted every woman to have a midwife like that. She came to my place every day for two weeks after the birth and not only taught me what to do and how to take care of myself and my baby but also practised it with me. You know, I was by myself with no family so that was really helpful. My baby was premature and very weak, so I didn't know anything at that time and this kind of service was something I really needed at that time. (W14)*

Overall, women wish to receive individualised maternity care in order to fulfil their needs and provide them with a positive and satisfactory experience. . Women believed they are well aware of their individual needs and consider themselves as the expert of their own health.

6.2 Involving women in their own maternity care

Women recognised the value of being involved in their own care, being aware of important milestones that lay ahead in terms of the care they were to receive and having some level of control over the decisions made at every stage of maternity care. The extent of this involvement varied according to the level in which women wished to be involved and take control in relation to decision-making. Some felt they were vulnerable, disempowered and dominated by maternity care providers and they let these providers take control of the situation. For example:

> *I told them [maternity care providers] but they didn't listen and put my baby at risk and did whatever they wanted…I just said yes yes. They never involved me in decisions and if I asked for something, they never agreed with me and there was a paper, they told me I have to sign. (W6)*

Some accepted their family members making decisions on their behalf, while others expressed their strong desire to be involved in a collaborative way with maternity care providers. Issues such as culture, personal attitudes, and emergencies were also identified by most women as factors influencing the degree of their involvement in decision-making. For example:

> *My husband and mother in law made the decision for me. If it was up to me, I would have chosen a caesar straightaway. I did not want all that pain and trauma, but midwife went with my husband and mother in law's decision without listening to me. (FGD1)*

6.2.1 Facilitating informed choice

Women wanted to be able to make informed choices even if they did not use that term. They wanted prior knowledge of all the steps involved in their care, the available options and wanted to be informed and educated about the risks and benefits of the interventions available to them. They thought this would enable them to make decisions with the support of maternity care providers.

Several women believed they were given the opportunity to make an informed choice based on information provided to them by their maternity care providers and they felt their requests had been taken into consideration. This was positive, as explained here:

> *I had all the options and for my daughter's birth I chose to go for a caesar because I didn't want to face any risks. I was able to say no when I didn't want something. I think I decided what I wanted. And they kept telling me what they doing for me I mean I was aware of everything they did on me. They talked about risks and benefits of every option. (W16)*

> *The doctor came and showed me a picture [of FGM] and said, "There is a problem you have too much cut [FGM Type3]. Your baby can come by normal delivery but you have a big problem". Therefore, before the time of delivery they cut [de-infibulated] me. The doctor said, it is like this, or like that, and explained everything they did. (FGD1)*

This level of engagement was important as women felt informed and able to make decisions. They thought all women should have such opportunities to make informed decisions.

The alternative to being able to make an informed choice was also highlighted by some women who gave examples of situations where choices and details about procedures performed on them were not given. For example, they described being given an injection, or intravenous therapy, without any discussion. Some women felt they lacked a level of control and that their wishes were not fully taken into account during their care. One woman said:

> *For me I have never been fully involved. They are always telling you things which they are going to do for you anyways. In my five births I don't remember a single time they asked me to choose this one or that one. (FGD3)*

Some of the women expressed their frustration at being unable to have control over their body. They described making uninformed choices, for example, undergoing a caesarean section without feeling that they had enough information on available options, as illustrated below:

> *The doctor said they couldn't find the baby's heartbeat. I said, "Listen, I am tired of these things; go for caesarean" And finally it was me who wanted the caesarean because when she put her finger in my vagina I felt a very, very bad pain because it is narrow and small due to FGM. Then I thought, "How am I going to get the baby's head out of this tight space?" (W12)*

Women believed that their maternity care providers should discuss a birth plan with them. In general, they felt fearful not knowing what was planned or likely to happen: 'We have a fear of uncertainty and not knowing what's going to happen next'. The women expressed it repeatedly for example, 'Let us know what is plan A, B or C'. One woman said:

> *They didn't explain to me what was going on during pregnancy. I always would like to know what is coming next, step by step. For example, in Week 4 you need an ultrasound, in Week 10 you need another one, and in the 26th week you need a blood sugar test and so on - - and why you need each one. They also should tell you if plan A is not going well and what is plan B or C or the next option. (W18)*

Several women mentioned that everything that happened to them during and after birth was unexpected and they were not informed about different situations or options, for instance:

> *Nothing should come as a surprise during delivery time… Tell us the different scenarios: if something goes wrong and we cannot go for normal, what happens and what other options are there, so that women are ready to deal with whatever comes next or what happens to them. For example, for me, I was not ready to stay there [in hospital] for 10 days and it was a big drama for us. (W7)*
>
> *We are going to do it, that's what they will tell you. No one asked me, do you*

> *want this or not, or are you happy with that or not. ...I remember they just came and checked and then went away but I wanted to know how I am, how my baby is. But they wanted to keep everything for themselves rather than sharing with us. Share the plan with us and tell us what you are going to do for us and what the options are. (W17)*

Women also indicated that it was important to them to be involved in their care planning and suggested that such a process might help maternity care providers to be more prepared for unforeseen incidents. In one focus group, a woman said:

> *I want them to make a plan together and I should be involved in making that plan, not just they make a plan and then give it to me… When I gave birth, they were not prepared for that [her FGM] because no one imagines what it looks like. No one checked me during pregnancy. They just waited for the baby to come and I was begging them to open me ahead of birth please, but she didn't do anything. (FGD3)*

Many of the women believed that if their maternity care provider had informed them and had made a plan involving them and if they had been made aware of all the available options, they would have experienced their care very differently, as highlighted here:

> *The midwife didn't plan ahead for a caesarean but because of my circumcision, at the last minutes when I went to the hospital, the baby couldn't come out because of my affected area [FGM] as I was closed. (FGD1)*

> *They need to give you some solutions or options for your FGM at the beginning, straightaway, not leave everything to the last minute. In my first pregnancy they did the vaginal examination at last at the end of my pregnancy. But before that they just asked the questions, they did not tell me even that they could open me up before that. (W5)*

6.2.2 Shared decision-making

Shared decision-making was a concept that women recognised as valuable and that they dreamed of such processes for the future. The level of involvement in decision-making depended on the situation they were in.

Many women mentioned that they signed consent forms for interventions like caesarean section, while experiencing pain and stress. They believed that their decision was heavily influenced by the condition they were in and did not count it as a genuine involvement in decision-making. These women explained:

> *They talk about things while you are actually in that situation because they don't assume things may happen beforehand. They come and ask you to sign a paper - seriously am I in a condition to sign a paper or make a decision while in extreme pain? To me it is not a useful way of involving me in decision-making. They can do all those things at the beginning and if they don't use all those paper works, they can shred them. (W13)*
>
> *She said, "Oh my God, this is very dangerous" and she asked me to sign so many papers and I said OK and even though I couldn't read English to understand what are those things I signed them. (W11)*

Women wanted to understand the risks of developing complications and to be given the opportunity to discuss their potential future decisions with maternity care providers ahead of the birth, so that the providers could also get ready, or could be part of decision-making with them. These women said:

> *When you go to the doctor, they should tell you even if 99% it will go OK and one per cent there could be a chance of complications. They should also tell us; we could do this or that. They should explain it and ask me also if I want it. (W2)*
>
> *In my experience there was no chance to make a decision or be involved. I want to know what the risks are for me as a woman with FGM. If something is going to happen to me make sure you give me all the information about that and you are prepared, not just come all on a sudden to take my*

> *signature. (W20)*

Many women felt their decision or requests had been denied or not listened to and that health providers followed what they planned without involving women in decision-making. For example:

> *They never involved me in decisions and if I asked for something they never agreed with me and if there was a paper for me to sign they told me I have to sign…I told them and they didn't listen and this put my baby at risk…they did whatever they wanted. They don't respond and they leave everything to the last minute. (W6)*

> *In my case, they did not tell me what they were going to do. They need to tell women if they going to open them or not going to open them. I was totally unaware of what was going to happen to me till the time of my delivery. (W1)*

Several women's statements showed how much they felt dominated by maternity care providers and the people around them. Sometimes this meant they felt they lacked autonomy and did not have the ability to refuse maternity care providers' requests, saying:

> *I wanted to be able to tell them [maternity care providers] I didn't want to walk in that corridor at all. Sometime they forced me to do things rather than gave me a choice. You know, like coming to me and saying you had to walk or take a shower or we need to give you this or that. You know, I want to have a control on my body and what I am doing while they were providing services to me. (W13)*

Many women perceived that their lack of health literacy and knowledge about access to certain options or health services led to their exclusion from decision-making. These women explained:

> *I never made any decision because in my first one I didn't know anything and was not aware even of what they had done on me; but the second and third time, they should have asked me… That's rude because it's your body*

> *not theirs. (W2)*
>
> *... I went in blindly and came out with a caesarean which I signed for and let them do it because I thought I had to and that that was the only way for me. (W20)*

Another woman indicated that a lack of both knowledge and language skills was a constraint when making appropriate decisions. Women felt that they just did what were told, for example:

> *Sometimes you are in a position where you have to follow whatever they say. Maybe because our knowledge is limited and the language also is a big, big problem. (W18)*

Some women said that, in the event that they were not able to make a decision by themselves, the maternity care providers did not involve their partner. This would have been helpful, as these women explained:

> *They didn't ask me or say they were going to cut me or open me. Then they stitched me back. They did not even involve my husband to decide. I went to hospital and they told me to lie down and I gave birth and they asked nothing. (W1)*
>
> *She didn't tell me anything, not a single word at least to my husband who knows a bit of English, and I was wondering what is going on down there on my body. (W21)*

One woman mentioned how much she felt unheard by maternity care providers and how she was affected by others making decisions on her behalf. She explained that, despite her desire to undergo a caesarean section, the maternity care provider took note of her husband's choice that she should not have the operation. She described having to go through enormous pain because of FGM complications and then ended up with a caesarean section, explaining:

> *They went with my husband's choice and I went through all the pain and I ended up with a caesar because my water was broken and the baby had got stuck there. They did not listen to me, they listened to my husband. (FGD2)*

This theme elaborated women's desire to be involved in their own care and to have some level of control over the decisions made during their pregnancy and birth. Women felt issues such as disempowerment, culture, personal attitude, and emergencies were influencing their involvement in their care.

6.3 Accessing fair and equal health care

The need for equality and treating women the same way as other women was a common theme when women talked about their dreams for the future. Most of the women perceived having privacy, being treated as special, and having access to language support, as important attributes of fair and equal care. They wanted to be welcomed and treated the same way as other women regardless of culture or skin colour, for example:

> *I want all women here to be treated equally and no one should criticise a woman because of her skin colour or culture. I don't want them to ignore her and if she needs them, they need to attend to her. I just don't want her to feel bad. (W19)*

6.3.1 Treating women as equal and special

The women who had encountered the welcoming treatment in the health system expressed gratitude for the access they had in Australia to all the technologies and services that they might need for safety and comfort. They recognised that this was valuable for all women, especially those in their situation, for example:

> *We all had a package of information regardless of where we came from and all of us get the same information, either African or non-Africans, black or white, they always gave that information to us. They also gave me information about FGM as well, which was great. (W15)*

> *I thought I am the same as everyone else, which was nice, and they treated me with kindness and as if I was normal. They did everything they could do. I don't remember anything that should have been different. Everything was all right. Everyone was so nice I cannot think of anything better. I hope it is the same for other women like me as well because these women [with FGM] need extra care, they need specialised doctors. (W3)*

Women wanted providers who had a helpful attitude, kindness, having knowledge and skills and a high standard of professional conduct. These were all considered an indication of fairness and equality, as explained here:

> *I want doctors and midwives to be professional, I mean doing their job right in the way it is supposed to be for everyone to a high standard. They should have the knowledge, treating patients the same way for all. Sometime you go to see the doctor, they think we are not important, they talk to us like a machine for two minutes and then ask you to go out. (W20)*

There was a tension in women's testimonies between wanting to be treated the same and wanting to be treated differently. Some women wanted to be treated the same but with consideration of their special circumstances. For example, they mentioned that, during vaginal examinations, they wanted special attention, with more options discussed, compared to other women:

> *I wish when they do any vaginal examination, they feel our pain and do it gentle, not do it harsh and aggressive. You know, because it is very hard to put a finger inside while there is no space, even for one finger. Maybe they don't have enough experience and knowledge, maybe they should train them well. (W12)*

While women wanted to be treated with special considerations, at the same time they did not want to be labelled as different, as articulated here:

> *You know we have to have specific services available to us wherever we live*

> *but also, we don't like to be labelled as abnormal. When there is a name attached to the services then women might even avoid services because we think, "Oh everyone may see me there and point at me later". So, I think they can add services for us everywhere rather than just name one hospital or clinic for the women with FGM. (W12)*

A few women assumed that the private health care sector might provide equitable services despite none of them having used private services during their maternity care. They explained:

> *I have to use the public system because I don't have money to go to a private hospital. In private system they may listen to me but I don't have money. (W6)*
>
> *This time I would go for private hospital. Because I think they care a lot. I haven't been in private hospital but my assumption is they are better than public one. I've got friends who had a birth in the public hospital with lots of complications and problems and I have friends who went for the private hospital and they had very good experiences, like they said: it is clean, the beds are nice, if they have an appointment they don't need to wait, the doctors are more experienced and they do not have trainees or students. All doctors are specialists there even the nurses are high standard you know. (W7)*

The examples in this sub theme elaborates women's experiences and desire of access to equal and special care in relation to their FGM. The comment 'are not normal' was frequently expressed by women.

6.3.2 Receiving language and interpreting services

Women desired access to interpreting services and they believed it is their absolute right to access these during maternity care. They mentioned language support services could contribute to equitable care and better health outcomes. For example, women said that using an interpreter during maternity services supported them in the understanding of health information and instructions, enabled them to make informed choices and helped them to access all the services available for them:

> *We [Women] should have access to all services and the chain of communication. If it is not in English, we should have access to any language [services] we need and have a choice about who should interpret for us. We need to be given all the options and be informed about everything we need to go through. (W16)*

Many women felt that language was a barrier to understanding the health system and expressing their needs:

> *If I am Sudanese, I wish to have the interpreter from Sudan; it makes the communication much easier. Even people who came from cities might not understand the language used by those who came from villages. That would be great if we could have that opportunity to have someone from our own country as interpreter. (W2)*

A desire to have access to an appropriate level of language support and interpreting services was emphasised in this woman's ideas about the services she would like for her daughter in the future. As she said:

> *She [her daughter] should be treated like everyone else and receive the same sort of services. She should have access to all the services and a chain of communication. If it is not in English, she should have access to any language she wants and have a choice to choose who should interpret for her. She needs to be given all the options and be informed about everything she needs to go through. (W16)*

Due to language difficulties many women noted that they were not aware of their rights and this affected their access to equal care, for example:

> *You know when you are new in a country you don't know really what is*

> *available to you and what are your rights. By the time I realised I have a right to ask for certain things, I had just finished any plans to have more babies. (W17)*

Some women mentioned they had difficulty communicating in English and in understanding the medical terminology used by providers during maternity care. These women believed they had to have a passive role in communication, as they did not understand the technical language used by health providers:

> *She [the midwife] came after a while and stitched me... She didn't tell me anything not a single word at least to my husband who knows a bit of English and I was wondering what is going on down there on my body but still today I remember the pain I had at that time. It was worse than circumcision pain believe me. (W21)*
>
> *My English wasn't good and I asked for someone who speaks my language but there was no interpreter. I was stressed because I did not understand the information, they had given me. At that time, I did not know even what FGM means when they talked about it. I needed someone to explain it to me. I just got some of the body languages like this and that… [Used her body gesture]. (W2)*

These quotes and experiences highlighted what women wanted and dreamed for the future – better access to interpreting services would make communication effective and clear and improve equal access to available maternity services.

6.3.3 Providing privacy and respecting confidentiality

Women desired privacy and recognised this as an important attribute of quality of maternity services. Most women experienced a lack of privacy during maternity care, for example, when their body was exposed to others while they were undressed, or if they had no access to a private room.

The issue of privacy was connected with access to a private room. Women believed that having access to a private room, being with their family, having easy access to facilities, and having religious needs addressed would help them to relax. For example:

> *I wish to have my own room or space with enough privacy with my family and access to the bathrooms without being worried that someone else is waiting outside. (W20)*

Provider consideration of privacy based on religion was important to women. Those from a Muslim background felt that they could not relax while they were in a shared room after the birth of their baby. They said:

> *We had to wear Hijab all the time because, they put us in a room with others and we couldn't take off our Hijab because the next person's husband was there so I was not [able to] relax really. And seems nobody care. (W17)*
>
> *It was so hard to put my scarf on immediately so I just kept it on all the time. That's why I just stayed overnight and then I asked them to let me go home because I didn't feel comfortable. For me the privacy was not really good in staying there. (W8)*

Almost all of the women in the study felt that their privacy was affected when, immediately after giving birth, they were put into a room shared with several other women from different cultural backgrounds.

> *In some cultures, they have lots of visitors and in some cultures they don't. Then if you put these two groups in one room, they both might suffer. You know you need that privacy after birth because you are so tired and have pain. (W18)*

Women frequently described being disturbed by noise and their privacy being violated by maternity care providers. This was described as:

> *I wish I had a room by myself it would be great. Sometime the other patients*

> *are very noisy and you know I couldn't sleep and the nurses were very annoying sometimes and they are like coming every 10 mins to check you so you never get a good sleep in the hospital. A room by myself would have given me the chance to sleep and relax and you know after giving birth you are tired and you want to rest and you want to get your scarf off, change your clothes'. (W3)*

Women wished to be allocated interpreters who are outsiders to their community. Use of a person from their own community was believed to violate their privacy and confidentiality, as explained here:

> *I grew up here since I was a teenager and I integrated into Australian culture so my situation is different. But I would say that if I was in need of an interpreting service, I wouldn't use someone from my own community who might spread the news among others in the community and violate my privacy. While in the hospital, they keep calling in people from your community. If that's for a support group of women who I trust I don't mind, but I don't trust a random person from the community as an interpreter for my private moment of life. You know confidentiality is important. (W16)*

Summary

Women reflected on their experiences of their maternity care in Australia in order to 'dream' about what would constitute quality maternity services for women with FGM. This included the wish for personalised care with services adjusted to address the needs of the individual woman and respect for each birth as a highly individual and significant event in a woman's life. In practical terms, women described how individualised care should mean the provision of support services for women following de-infibulation. Many women identified how body image and culture affected their desire to be re-infibulated and how they would like the removal of legal barriers to this process.

Women expressed a clear understanding of the need for services to facilitate informed choice and shared decision-making in a way that involves women with FGM in their own care. They wanted to be treated in the same way as all women accessing Australian maternity services, but with consideration of their special circumstances due to their FGM and potential barriers related to language and communication.

Women wanted services to be sensitive to the need for privacy and with respect for confidentiality. Although not specifically related to FGM, women considered privacy important to quality maternity care to ensure religious practices were followed.

Women appreciated the fact that the Australian maternity care system supported women to have a normal birth if possible. Many expressed the desire to avoid caesarean section through timely de-infibulation in pregnancy.

The next chapter builds upon women’s descriptions of ideal maternity services and consider as practical issues in planning together around the ‘design’ of quality maternity services.

Chapter 7: Planning together for improved maternity services (Designing)

Introduction

The ‘design’ phase of AI invites participants, individually or as part of a group, to develop a plan for what they need or wish to happen to achieve their dreams. In this study, women were encouraged to think strategically about how the maternity care system can be changed to improve the wellbeing and experiences of women with FGM. Suggestions included addressing cultural integrity, information systems, emotional support, and effective communication. This stage enabled women to provide examples of their experiences that they had not necessarily disclosed in the ‘discovery’ and ‘dreaming’ phases., Table 6 illustrates the main themes that emerged in this ‘planning together’ phase.

Table 6: Planning together for improved maternity services (Designing)

7.1 Promoting cultural safety practices through education
7.2 Implementing midwifery continuity of care
7.3 Improving communication and emotional support

7.1 Promoting cultural safety practices through education

A number of practical ways to design future maternity care systems to improve cultural safety were highlighted by women. ‘Cultural safety’ for women also meant having maternity services that are physically safe and spiritually, socially and emotionally sensitive. The women believed that they had their own special culture surrounding birth and motherhood and maternity care providers should be mindful of this in order to fulfil each individual’s cultural needs.

Women regarded the provision of culturally sensitive care within Australian maternity services as of upmost importance. They identified a number of areas where training and education in cultural safety should be mandatory for maternity care providers, including education about issues related to FGM. Women agreed that midwives needed to have prior technical knowledge and skills as well as cultural competence when caring for women from diverse cultural backgrounds, for example:

> *Many of those midwives themselves need a lot of training in order to provide us with good care. Updating their knowledge and tailoring this to the needs of the community is very important because if a midwife will work with different cultures and races, they should be well prepared and trained. (W13)*

Women felt strongly that maternity services should make efforts to design educational initiatives to enable staff to question their attitudes and learn about how these might impact on the quality of care provided to women with FGM. In particular, the need for providers to be non-judgmental about cultures where FGM is practised, as articulated in a plea from this woman:

> *Don't criticise us because circumcision is part of our culture and it is a duty for us to do that because that make us the same as others in the society. It harmonises you with your community you know so it is good within that culture. Of course, in this culture [Australia] it is seen as bad and we shouldn't do it for the same reason to be part of this society. But if we did it in our country and now we are here with circumcision they should count us as part of society and not blame us. (W19)*

Participants often raised issues such as discrimination, and the reactions of maternity care providers. This was attributed to the lack of knowledge among providers. Many women recalled how maternity care providers' emotional reactions, including a look of surprise on their faces, made women feel uncomfortable, stressed and judged for having done something ‘wrong’, for example:

> *I remember the first time when I went to the hospital the doctor looked at me and was shocked and said, “What happened here?” I said to her that this is done in my country for all women. The health care provider should consider that and don’t treat us like we did something wrong. This was done in our tradition when we were a child. (W11)*
>
> *I remember how much it was stressful for me. I don’t want for any woman to feel like that. Being in a new country and facing Western culture and lots of other things… During my birth when the midwife was about to break my water she said, “Oh my God, you’ve got an FGM!” I remember she was very surprised and panicked just seeing my vagina. (W20)*

Women clearly believed that cultural safety was an important element of care in a multicultural and diverse setting such as Australia. Specifically, to improve maternity experiences for women who have undergone FGM, they encouraged educational initiatives for maternity care providers in order to improve their understanding and familiarity with the cultural beliefs behind this practice, as these women explained:

> *If I am a midwife, I make you feel good and I need to understand what you believe in so I can understand if you see FGM as a good thing or bad thing. Then I can talk to you and guide you accordingly… first you need to get a sense of what women believe in, otherwise they may not disclose anything. (W12)*
>
> *This is such an important topic and we want also a health provider and health system to speak for women and help women to understand it is OK and that they are not alone, and to ensure them that they have access to social and clinical support. So, if health providers just learn about cultures around them, I guess they can deal with this issue more effectively. (FGD3)*

Education programs were seen as important in addressing the chief barriers to change that is, cultural taboos about discussing issues related to FGM. They expected maternity care providers to initiate discussions about FGM, rather than waiting for women to initiate those discussions. Two women explained why this was important for safe care:

> *I mean my circumcision is part of my culture and the doctors and midwives need to learn about it but they did not. What is happening in our culture is that the women don't talk openly and especially if it is about circumcision and that sort of stuff, they may not talk openly to a stranger. They [maternity care providers] need to learn about all of these cultural needs. I also hide my FGM till birth and no midwife or doctor bothered to talk to me about that otherwise I might have opened it up. All my communication with them was yeah yeah yeah and leaving the room without understanding what they said to me. (W23)*
>
> *Some women when they have some scar there [pointing to her vulva] or some infection women are ashamed to talk about it. Culturally we are not used to talking about those things and it is a shame to talk about it. (W20)*

Women felt strongly that all women from practising countries should be asked about FGM and physically checked by maternity care providers and that this should be recorded in their maternity records. These two women highlight the importance of designing systems that promote good documentation about women's situations regarding their FGM:

> *All women should be asked about FGM as part of their history no matter white or black. And it should be written in bold in their file. And all providers should make sure they examine women in that area because sometimes there are cultural reasons why women may not tell midwives about it - so they have to check physically. (W20)*
>
> *I want them this time to have the whole of my history in the computer in front of me and we can all together go through it and if my doctor and midwife have questions, they should ask me at the very beginning. And as soon as they put my name in the computer it should come up and I should not have*

> *to explain everything from scratch each visit. (FGD3)*

Women also mentioned that, while maternity care providers need to be respectful of cultural issues and integrate this respect into their services, they also need to be mindful of harmful cultural practices which may place women at risk. For example, in some cultures, women do not use direct communication to explain their problems related to childbirth, maternity care or FGM. There were many women who mentioned that they avoided disclosing their FGM as they thought this was culturally inappropriate:

> *I was shy and hide my FGM until birth and I am sure many other would do that. In our culture women won't talk about it believe me or not. There is shame and stigma with those topics. (W23)*

> Women wanted maternity care providers to be educated about cultural sensitive maternity care and be able to discuss FGM openly with each woman. This includes the provision of information about the harmful effects of FGM, even if this detail was not culturally acceptable for her. *A midwife should know how to talk to us and treat us in order to remove our anxiety and fear. They should talk openly and make it like a normal subject. I know they think it is culturally appropriate to not talk openly but as a woman from those cultures I appreciate straight forward and open discussion about this issue. They should explain to me what is my situation in my body in relation to my cut and what potential risks there are and how to remove those risks. (W14)*

Several of the women suggested that redesigned maternity services should include education for maternity care providers regarding the law and FGM. Some reported that maternity care providers performed re-infibulation on them after the birth and a few recalled that re-infibulation had been offered to them despite the fact that it is illegal in Australia. For example:

> *I even remember the midwife asked me if I wanted to be closed back because*

> *she said some African women wanted to be closed after birth. You know in some African cultures' women need to be closed after birth because when they have sex with their husband they might not be accepted if they are open but in some cultures, this is not required. She [the midwife] said she usually stitched the Somalian women back and closed them again. I said not for my culture. (W15)*

> *After my first birth I did cosmetic surgery and make it open, but after my second baby's birth they again closed me back the same way it was the first time. I did not know it is illegal in Australia. (W6)*

Many women believed that the maternity system and should be designed in a way that all were aware of the legal aspect of practice of FGM in Australia. They recognised that some women were taking their daughters overseas to have FGM performed and that maternity care providers could play a role in preventing and advocating against this practice:

> *To be honest I wonder how we can control and stop this practice [FGM]. They do it secretly. For example, if someone goes to their country and comes back to Australia no one will check so they would not know of course until that girl gets pregnant. But still the system has to ask the question of how a girl who was born here is cut. (W18)*

Women suggested that culturally sensitive care should be part of maternity care providers' education programs including ongoing continuing education initiatives. They also believed that communities can be a supportive resource for providers to learn about their culture if they are prepared to build relationships with them:

> *It is good for the health system also to be culturally sensitive by training midwives, doctors, and nurses in cultural sensitivity. Especially for the midwives it should be part of their course. They need to learn about other cultures rather than treating everybody under one framework. They need to find a point of contact with communities and ask how to help them: trust*

> *them and ask for help. (W16)*

7.2 Implementing models of care that provide midwifery continuity of care

Continuity of maternity care was one of the models of care or services most appreciated by women who received it. Word ‘midwife’ and known face was frequently expressed by women. However, most women did not have access to such a model of care. Midwifery continuity of care was understood by women as being cared for by a known ‘midwife’ over the entire period of pregnancy and childbirth and after birth. Being with the same midwife and building a relationship based on mutual trust and understanding was perceived to improve women’s sense of safety and confidence and increase their involvement in their own care. Women suggested that maternity services should be designed to enable all women to have access to such a model of care, for example:

> *It is very important for women because we want to trust someone and by changing midwives and doctors we will be lost. I will also develop my confidence in her competence and make sure she can manage my birth and I am in safe hands. That’s a huge support for me knowing that I am safe and someone knows my issues and concerns. (W17)*
>
> *I don’t think I was able to build a relationship with a doctor and midwives because they always changed. You know, because every time the person changed, I just go to check to know if that’s OK or not. I would like one midwife to be in charge from the beginning till the end of my pregnancy. I would feel safer because she knows well about me not just based on my history. (W8)*

Some of the women recalled that receiving midwifery continuity of care was the best part of their maternity care, as articulated by these two women, for example:

> *With that one midwife who cared for me the whole pregnancy, still she is calling me and I am calling her; it was like a friendship. And after 6-7 months she was always telling me I am here whenever you need me for anything. My third birth was really the best. (W2)*
>
> *I saw this midwife every time I went to hospital for a check-up and I really liked that because she knew the whole history of my pregnancies and my problems. I didn't need to repeat it every month to someone different. (W11)*

Another woman enjoyed having continuity of care with one midwife who had specialised skills in the management of FGM for both her pregnancies. She said:

> *You know to be with one midwife with both of my two births in Australia was another excellent thing. When I went to the hospital I stayed with the same midwife over time and even for my second one I was still with her. I think she was looking after people with FGM as I realised she was used to looking after women from my community also. (W15)*

A few women compared their first experience of midwifery continuity of care with previous pregnancies where they had had no access to continuity, for example:

> *I remember there was only one midwife during my whole pregnancy who provided care for me. And she did all the check-ups and did the birth. This was in my first pregnancy. For the second one I saw different midwives. I liked the first experience because the midwife checked me all the time; I got used to her and she knew everything about me and I am more happy. (W3)*
>
> *I have seen different hospitals with different services. I had my first baby in Bankstown and the second in Campbelltown and I had a much better and different experience in the second birth because one midwife looked after me all the time. I had a nice midwife who always came to me and looked after me and asked me how I am because of my bleeding. I felt she got all the skills I needed and I trusted her. (W1)*

Most women wished to have midwifery continuity of care as they associated this with building trust, comfort, provider familiarity with their background, and saving time by not having to repeat the same history at each visit, explained by this woman:

> *I love to see one face all the time during pregnancy and birth. Because different faces have different ideas. But if you see one person it is very good because she knows everything from the beginning till the end. But always new face, new face, new face, new idea, new idea, new idea. It is very confusing and scary for us. (W9)*

There were a few women who received midwifery continuity of care during pregnancy but during labour and birth their known midwives were not present. They expressed feelings of anxiety and distress with being cared for by midwives they had not met before during labour and birth, for example:

> *In my last pregnancy I was a bit worried because I did not know the other lady [midwife] and the other one did not care for me again and I gave birth with a different midwife. I liked the care one midwife gave me throughout my first pregnancy…I was more used to her as I saw her every month and I felt safe maybe. (W3)*

Having different midwives through pregnancy, labour and birth was not seen as an ideal system and women expressed their frustration with repeating the same history of FGM each time to a different maternity care provider:

> *You know sometime you are with a midwife and when the next session comes you plan to ask some questions and share your concerns and all on a sudden someone else will take over and you need another session to build trust and orient her about everything and then it changes again. It is frustrating. Each time when I come to you [maternity care providers] you need to remember all the information I gave and not ask me the same things 100 times. You need to make sure you follow me through pregnancy and childbirth continuously. (W20)*

Some women mentioned that each time they saw a different midwife, the midwife spent most of their time looking at their notes and learning their history of FGM rather than communicating with them. This was frustrating and distressing, as explained here:

> *I was cared for by different midwives at each visit and also during the birth. I wish it had been one midwife all through. Each time I had to answer the same sort of questions. Each visit they spend more time collecting your history rather than talking about other stuff. And instead of looking at you, their eyes and head were in your file rather than communicating with you. (W20)*

A few women did not know whether midwifery continuity of care was available to them but upon learning that this was an option, indicated that they would have preferred this model of care, as this woman explains:

> *If I had known that I had the option to be with one midwife during the whole pregnancy I would have chosen it. I would really have liked to receive care from one person. (W8)*
>
> *In the public hospital you always see someone different each time. There is no time to be a friend with one of them and talk about my issues. I would like it if I had an option to choose my midwife and go with her for all my pregnancies. That's a nice thing if they could do that for us. (W23)*

During the focus group discussions, women repeatedly expressed the need to design maternity services that enable midwifery continuity of care. One woman however, thought that there should be an option for women to choose or change their midwife if they wished:

> *[If I were a midwife] I would take care of her (the woman) all the time if she is happy but give her a choice to change if she is not happy or comfortable with me [as her midwife]. (FGD3)*

This theme elaborated women's experiences and views on importance of midwifery continuity of care. Most women had not received midwifery continuity of care but those who had received such continuity of care, appreciated this service model.

7.3 Improving communication and emotional support

Women viewed high-quality maternity care in terms of the way that maternity care providers behaved towards them. Considering the sensitivity of a topic such as FGM, the women believed positive and effective communication was a key component of maintaining a sense of connection, trust and collaboration with health providers. For example, they wanted to be heard, touched and welcomed. Many women indicated that building trust happened over time as they got to know their maternity care providers through their direct interactions. As this woman explains, this was especially important in addressing the embarrassment that many women felt because of their FGM:

> *You know little by little each time after I started to visit the doctors and midwives and they didn't make me feel embarrassed and they asked me so many questions when I went to them. And the way they talked to me was so good. You know, you feel so good when someone listens to you. They were not in a rush to get to the next patient and kick me out of their office. They spend time with you and do what they need to do while they kept privacy. (W13)*

Some women raised concerns about ineffective communication and due to inadequate time allocated for women to spend with their maternity care provider. They believed that addressing workforce issues and utilising community-based social health workers would improve communication between women and the health system. One woman said:

> *The waiting time to visit the doctor and the midwife is so long and when you go inside, they don't give us enough time to talk and raise our issues; they are in hurry to finish and ask for the next woman. They need to have more staff not just doctors and midwives, you know they should also recruit social*

> *workers in between, so women have someone to talk to if they need. The social workers can talk to them and provide counselling. (W20)*

Many women felt that there was no transparent, clear and mutual communication between them and their maternity care providers. As a result, women were often suspicious of the maternity care services they received and were not always willing to accept advice from providers, as illustrated with the following quote:

> *Sometimes women are too sceptical about whatever doctors and midwives are doing for them. While most of the time they do the right thing but still women take it wrong when there is a lack of information and communication. If the midwife tells me the reason behind not opening me, I would accept it but if she just forces me to do something it is not acceptable for me. (FGD3)*

For another woman, a lack of communication about FGM indicated a lack of knowledge and skills of health providers.

> *Sometimes they don't even talk about FGM with us and just write everything down and say all is good without giving us the details. I think it is mostly because they don't know anything about FGM and they just look at you and they have no idea. (W17)*

Some women felt that, due to their low literacy level, maternity care providers were reluctant to share detailed information with them about FGM:

> *They're really good for follow up and controlling you but they never communicate things [about FGM] with you. Maybe they think we are not worth it or not educated enough to understand. They should explain all the risks which may accrue during pregnancy. (FGD3)*

Women requested that maternity care providers simplify their technical and medical terms to ones that women can understand and that maternity care interpreters with specialist knowledge of FGM should be employed. They believed that, with such services, they might make different decisions. This woman explained:

> *Even if I have very good English it is not enough within the health system because they always use terminology which we don't understand. They should modify their medical language to the level of community literacy or English language skills. We are not experts or specialised in everything like obstetrics, neurology, FGM and so on. Sometimes even the interpreter doesn't know what FGM means. You need to have a specialist interpreter instead of using one interpreter for everything. Sometimes one word could change your whole decision. (W18)*

In designing maternity services for the future, the provision of emotional support was one of the most important factors that women identified as necessary to quality care in this study. Women wanted to receive emotional support to address their trauma including dealing with health issues related to FGM. Women's satisfaction with maternity services was strongly influenced by receiving emotional support that included touching, and interactions that were friendly, kind and helpful.

Women greatly appreciated maternity care providers who were aware of their feelings and emotions and able to consider the trauma they had been through. Most of the women expressed their need for someone to simply provide a listening ear, with referral to counselling services where needed:

> *Sometimes you just want someone to talk to and ask for nothing else, just someone to ask you what your feelings after birth are or how you are because it is a hard time. ... I want a midwife or nurse to provide care for me beyond giving medicines, I want them to talk to me and support me emotionally and mentally. (W17)*
>
> *I would like to have access to counselling after birth about my situation. You know sometimes all you need is to talk to someone. (W19)*

Most of the women believed that management of their distress and anxiety due to their

FGM was critical. They suggested that maternity care providers needed to be adequately prepared and knowledgeable about the emotional effects of the trauma women may have experienced, as this woman explained:

> *They need to know all the psychology behind pregnancy and birth and develop a good relation with women. For us, apart from the changes of our body and all the other issues around pregnancy, we also have suffered from another traumatic experience which makes us extra worried. These doctors and midwives need to learn how to deal with such cases (FGM). (W20)*

Women believed that their past traumatic experience had left them with a lifetime of pain and psychological complications and that they needed someone like a midwife to be close to them and talk to them and provide them emotional support:

> *I wish midwives and nurses and doctors would be kind to women from minorities like us. These women are traumatised in many ways and they need to be friendly and close to them, touch her, hold her hand, talk to her and ensure her that everything will be fine and she is in safe hands. I guess midwives are the most important group who needs to be close and kind to these women. (W20)*

Under this theme, women expressed their need for emotional support through clear communication and supportive and empathetic care.

Summary

In designing future maternity services, women were clear about the need for education initiatives that enable maternity care providers to promote cultural safety and communicate in ways that are appropriate for supporting women with FGM. In particular, women identified the need for guidelines that optimise a range of emotional support structures.

The benefits of designing maternity services that enable all women to have midwifery continuity of care were clearly outlined by women. This included the particular advantages for women with FGM.

In the final findings chapter, women draw on their experiences and suggest actions to mobilise and enable communities to strengthen maternity care systems and improve services for women with FGM.

Chapter 8: Improving and sustaining maternity services (Developing/ Deploying)

Introduction

This chapter reports on the role women saw for themselves, their communities, maternity care providers and governments in supporting plans to improve the quality of maternity care for women affected by FGM. The women focused on what they thought needed to be changed in the long term and how the behaviour of maternity care providers might bring about positive outcomes for women with FGM.

The findings in this section are focused on community mobilisation and women's empowerment in their efforts to prevent and stop the practice of FGM. Women suggested that there should be greater efforts to sensitise the community and policymakers about FGM. The majority of women considered that positive change to improve the health of affected women could be achieved through a multi-dimensional approach, one that would engage women, men, and communities. A summary of the sub-themes is presented in Table 7.

Table 7: Improving and sustaining maternity services (Developing/Deploying)

8.1 Mobilising and enabling communities 8.1.1 Advocating, educating, campaigning 8.1.2 Involving men 8.1.3 Empowerment of women
8.2 Strengthening maternity care systems
8.3 Increasing government support

8.1 Mobilising and enabling communities

Women believed that communities need to be mobilised to create a supportive environment in which pregnant women and new mothers affected with FGM can feel safe and healthy. Advocacy and campaigns for policy, professional practice and at a community level were considered critical in creating a supportive environment to improve health outcomes for women in the long term. Participants described the empowerment of women and the involvement of men as necessary elements of societal change. It was recognised that the success of community-based interventions, such as education and media campaigns, depends upon the involvement of all members of the community including religious and community leaders in the planning and implementation of processes of change.

8.1.1 Advocating, educating, campaigning

Raising community awareness, through formal and informal education, campaigns in the community and schools, and involving women, men andyoung people, was considered essential to bringing a positive change in the health of women affected with FGM. The women believed that their communities played a key role in creating a supportive environment, as they explained:

> *…we must educate our community to have more strong people so we are able go out and talk to the [Australian]government about our issues related to FGM and how we can educate communities. … even if we don't have funds or money. We can also ask our husband and sons to talk about this when they get together with their friends. (FGD3)*

> *Still many people in the community believe it is a good thing to do on their daughters [FGM]. … I will not let my daughter to undergo FGM but we need to remove pressure of the community on families. If no one wants a girl without FGM then everybody forced to do it. We need to end that by*

> *educating community and change this culture. (W22)*

Community education about cultural norms in the host culture [Australia] was highlighted, as a way of creating a positive impact on FGM by changing attitudes towards FGM, as indicated here:

> *Our community also need to integrate in this culture and remove all bad cultures like FGM. And be part of society and harmonise with others. Some people, they know it is bad, but still they believe they should do it. They put the culture over their health. (W20)*

Some women gave examples of the positive impact of the training they received about FGM had had on their personal life and recommended this kind of training for all communities:

> *The community needs that sort of training. I attended a seminar in 2014 and it was just eye opening for me. The whole community needs to know that [FGM] is wrong in any country, culture or religion. (FGD2)*
>
> *I used to be very shy to talk about my FGM but after receiving FGM training through government I started to talk about it and expressed myself and also asked and encouraged other women to talk about their issues openly. This way people in our community will also start talking about it. Oh yeah, have you seen that program? It will be an open subject within communities rather than a hidden problem. (FGD3)*

However, many women indicated that they had never received or heard of any kind of training about FGM at the community level. To address this, one woman believed that community gatherings and festivals would offer the best opportunities to reach and informally train wider and more diverse groups of population. She said:

> *I am here for 14 years and attended so many festivals, workshops and training for our community and sometime a huge number of people attend those events but no one talks about FGM there. It is a good opportunity to*

> *raise awareness. It might not be enough but still good places to advocate. If they don't do it during our festivals they are not going to access all people within the community. We have for example a New Year festival just once a year, which most people in the community attend, and that's a great opportunity to open up this kind of conversation there. (W20)*

Identifying individuals and champions and key players in the community who are supporting and advocating against FGM practice is another strategy suggested by the women as a method of protecting girls from undergoing FGM and achieving community involvement. However, women believed without the technical and financial support of the Australian government, implementing such advocacy campaigns and activities within the communities would be challenging. One woman said:

> *We can educate people within the community to advocate for us at a higher level, to transfer our voice to government. Or even if we have enough educated people who can talk to other people within their community, that could also be enough to change this. And no one will do this practice. (W23)*

Women also suggested establishing different networks and groups within the community who can foster changes in attitudes to FGM, for example:

> *We need to talk to community leaders or elders to find a support and trust group within the community so we can reach up to them when needed. (W16)*
>
> *Involve young people to talk about this issue with their friends. Establish group discussion in the community like an FGM support group or something like that. The more we speak the more we learn about it and how bad it is. (FGD3)*

Women believed the practice of FGM was continuing in their communities even in Australia and that this practice will not stop unless steps are taken to start conversations within families and with their children. It was clear that families have a central role in bringing a sustainable change to stop a culture such as FGM, as explained here:

> *Change is dependent on families. In my family I have already talked to my kids about the stuff like FGM and the even bigger impact of it on society. I think that's how we will spread the word and stop it, otherwise it is never going to be stopped. Now people believe in this society that talking about this issue is wrong or Haram [prohibited by religion]. I don't care; I will talk to my children because I don't want them to grow up blindly. (W18)*

> *I explained [about FGM] to my daughters since they were four or five. And I explained to them that their grandparents may insist on doing that for them but I took a stand and said no and now they should say no in the future. ...I think parents have a role to communicate more and more about this within the family and with relatives and make it open and clear for family member that this is not a good culture and it has to change. (W14)*

Most of the women believed that the next generations will not continue the practice of FGM, as they are educated and are aware of the harms and risks associated with this practice, as stated in this quotation:

> *Families need to get together and strongly be against FGM. They need to talk to their children and train them that this is not good for them, then they can go out and talk to the community. Change starts from each family. I talked to my girls already and they were shocked but I am sure my child will never do this practice on their kids and I asked them to tell their friends about how bad it is. (W23)*

Women believed that if their children were aware of the harm of FGM then they would act as advocates against FGM among their friends and students in the community. One woman explained:

> *I already talked about it to my son and daughter and they know we are against it. I am sure they got the message and they will pass the message on to their fellow friends and classmates; that is how we educate people. Change starts with your own family then it will go to the community and everyone else. (W15)*

The women indicated that, in order to raise awareness within the community and health system, a platform is needed for people to open up and discuss the issues associated with FGM. Suggestions included these:

> *The topic is very sensitive. Women may feel uncomfortable and shy to talk about it but I hope if everybody can open up a platform and talk about the issues then everybody will know about the problems for women and can solve them. (W4)*
>
> *Now I would tell everything to my friends and relatives. I tell them not to touch their daughters because it is very dangerous. I tell them about my life pain because of this practice. I don't want any girl in Australia or even in Somalia to do this. Now I know most of my community here don't do it but still some do. We live in Australia; it is an open society and we are free. (W9)*

Women recommended campaigns with wide coverage and different forms of media. Suggested strategies included community visits for health providers, hospital open days for community members, and the use of social media to share and promote the stories of women who have suffered because of FGM. Women saw such initiatives as effective ways to get communities involved and raise awareness, for example:

> *We need to close that gap between health systems and the community by bringing doctors and midwives to the community to talk to people - men and women. And all women have to bring their husbands to the workshops or training. They can hold open days at hospitals so everyone can go and ask their questions and raise concerns. They can use the media and put up visual billboards around the community so people can look at these and understand the problem and the solutions. Lots need to be done. We can ask women who are victims of the practice to share their stories in the media and raise awareness. (W20)*

Most of the women believed that the media can make FGM a more visible issue and play a key role in creating a momentum for open discussion and change.

> *They spend so much money on TV advertisements and yet keep this issue as a secret. What they could do is just put a 10 second advertisement on TV and explain this issue to the Australian society - what it is and why women are suffering from FGM. They could go to the hospitals and ask health staff about it or even women could talk about their problem. If they make that sort of documentary on the TV or make video clips for TV it might have a bigger impact on society. (FGD3)*

> *There was a documentary on SBS about this and I remember it was very eye opening for the community and everywhere they were talking about it. I mean, the government is the main actor who can create that platform for the community, to open up conversations and talk about this issue in order to improve women's health. You know if you make the community aware of their health needs I reckon they would automatically engage. Leave the responsibility on them - they will manage it. Just provide them with the resources they need to engage, such as a place for workshops and trainings and documents. Talk to them, listen to them and be in touch with them, that's all. (W18)*

This section highlighted the women's emphasis on strategies such as championship, community and media campaigns, to improve health literacy and prevent continuation of the practice of FGM.

8.1.2 Involving men

Men were regarded as important actors of change but women thought that they were lacking in knowledge about the consequence of FGM on women's bodies and minds. Women felt that men believe that FGM is women's business and that they are enforcing the continuation of FGM due to cultural obligation. The women, therefore, perceived that men's involvement is a crucial part of the solution to end this practice despite the fact that it might be very challenging and difficult as men are not interested in taking part in such a movement. Examples such as these were given:

> *Men in our community are part of the problem for continuation of this practice. We need to involve them and train them and raise their knowledge. Men have always wanted the women to be cut but when you ask them about the issues they don't even know – it's something that just goes into their mind generation by generation. We need to change that. I am telling you it is still happening and it is secretively done and hard to catch people. It is connected to culture and I don't think families will give it up. (W20)*

> *It is shocking that they even take their girls from Australia to Somalia to do it. It is very sad. The main solution is to stop it together by campaign and training. For my community it is a hard thing to do, especially for men. I think the health system needs to get men more involved in health services, talk to them and convince them to talk to other men in the community. (W11)*

Women believed that one way to educate men and encourage them to become involved in campaigns to stop FGM is to involve them in maternity care and ask them to be with their wives during antenatal visits. Examples were given by these two women:

> *If they involve our partner, the talk wouldn't end just there because he will see I am suffering and then it goes to relatives and they would get to know and we would all become against such a crazy thing. For example, my husband would take a stand and say my wife suffered but I won't allow our daughter to suffer and finally we can make a change in the whole society. (W13)*

> *My husband, for example, will never do this on his daughter because he saw me, how I suffered, and I also talked to him a lot about it. (W10)*

Women perceived that men's participation in preventing FGM is not encouraged including by health professionals in maternity services, as illustrated in the example below:

> *I guess if you educate men at first point they automatically get involved now.*

> *No one said to our men in the community that they need to be with us during maternity care. (W2)*

Women felt that more pressure should be exerted on men to be involved in pregnancy and childbirth. Involving men was regarded as important to counteract a patriarchal culture that considers FGM as a women's issue and where men remain uneducated about the consequences of FGM and are reluctant to get involved, as explained here:

> *I mean, it is a cultural thing that men in our culture are not involved with issues related to pregnancy and childbirth. But the Australian health system should force them to get involved - that's a good culture and we have to change ours. (FGD3)*
>
> *You know if our men are not educated on those wrong cultural concepts and ideas, they would never support women to stop the practice. For example, if on the first night of marriage they cannot get in easily that's a good thing for them and they would be proud that their wife is a virgin and clean. (W10)*

Women expressed the opinion that there is generally a lack of education for men in the community, which leads men to enforce the continuation of FGM. More education, awareness and information at a community level is needed, as explained here:

> *Men are very selfish in our culture. Because, they don't understand us and don't know what this practice does to our body. Men need to talk to each other within the community'. (FGD2)*
>
> *For men we need the same training and awareness we are doing for women because sometimes they are the one who push women to do it [FGM]. Believe me, some men don't even know that it is harmful they just know they should do it. You need to let them learn how bad it is, you know, governments need to put funding in for this issue for involving men and campaigns. (W17)*

Women believed there should be mandatory training programs before immigration, specifically aimed at men receiving all information about the legal and health consequences of FGM in Australia. They also suggested that informal training for men by their peers would be more effective than formal classroom training. Two women said:

> *You know there should be informal training for men. No men in the community want to listen to these kinds of thing but if you train a few men within the community to just go around and talk to other men informally that will works better than a formal class that no one want to attend. (W17)*

> *At the moment most of the trainings are for women. We need men to talk to men so we can engage them otherwise you cannot force them to sit in a class. You need to train more men to open up and talk about this issue with other men in the community and engage them at the same level as women. Men are still looking at it as a good thing. (W15)*

Women felt that families in their community still 'cut their girls' because men are not interested in marrying a girl who has not been cut. The cultural belief that makes their daughter marriageable and appealing in terms of sexual pleasure for men seems to be an important factor to address. This highlights the education needed at a community level to dispel myths as this woman articulates:

> *I will not let my daughter undergo FGM but we need to remove the community pressure on families. If no one wants a girl without FGM, then everybody is forced to do it. We need to end that by educating the community and changing this culture. (W22)*

One woman suggested that 'educated men' may reject women who have had FGM, wanting to avoid problems with sexual intercourse:

> *When I got married to my husband, he asked me if had 'khetan' (FGM) or not because he does not want a woman with 'khetan'. I said yes and told him, "If you don't want me just go, that was not something that was my decision". Educated men don't want us because of problems during sex but some men have this idea in their head that if a woman has had 'khetan' she*

> *is very good [value]. (W6)*

Women believed that a change in men's mindset can be achieved by starting conversations about the issue with young boys and men in the families and communities. In one focus group where this was discussed, a woman said:

> *You know, it is very important that your son will marry and he needs to know about that [FGM]. And even he can go out and talk to other boys in the community about it, which is the best way to get the message out to the community. I will teach my son if I have one in the future. I even trained my husband and he is now an advocate for stopping FGM in our community. (FGD3)*

Women also stated that men and women need to come together for an open and meaningful discussion in order to bring positive changes. For example:

> *In our culture men and women are segregated but they need to put them together and talk to them. For example, on Friday prayers, which men go to, they can ask women to join them and talk about this issue. (FGD2)*

> *There is no open discussion between men and women in our community at the moment. At least women are coming to hospital where people talk to them. Women talk among themselves and men don't even talk among themselves and at the end nothing changes. Maybe the government can start that discussion or even hospitals can do that by inviting men and other women talking about FGM and its problems. (W12)*

Women's accounts in this section explained the role of men on the discontinuation of FGM practice in their communities. They emphasised the importance of men's involvement as a strategy to overcome challenges and discussed FGM-related issues across gender.

8.1.3 Empowerment of women

Much emphasis has been given to raising women's awareness and literacy about their health and rights. The women in this study believed that if women are well educated then they will be empowered to influence their community and the society and ultimately improve health outcomes for themselves and for others. The development of female champions and engaging them to discuss this issue at policy and community level were some of the strategies outlined by the women to increase awareness:

> *[We need to understand] the importance of education for women so they can go out and educate other people in the community about everything, including stopping FGM. Educate the girls; they are young and if we want to change this, we need to involve young girls and boys. (FGD3)*

Some women believed that, after years of being in Australia, they were more aware and educated about their rights, and better able to stand up against violation of their health rights, saying:

> *You know, just being in this country for longer may change your mind a lot. Now I know my rights and I am more mature and if I go for another birth, I will demand good services, I will ask for an experienced doctor and midwife who know how to deal with FGM. (FGD3)*
>
> *This time I am more aware of the Australian health system and what are my rights. I know the language better so I will ask for whatever is missing or lacking, like a doctor, midwife and interpreter with experience of circumcision. (W23)*

Women who had been educated in Australia demonstrated their sense of empowerment giving examples of how they had influenced relatives, family and neighbours to transform their stereotyped perceptions of FGM. This was illustrated by saying:

> *One day my mother planned to get my sister's daughter cut but my sister stood up to her and said, "Don't touch her". And my mum said, "You will see that no one will marry her and my sister told her, "That's her business, not mine and yours and don't worry, she will find her way". After that, my*

> *mother still don't talk to my sister. Thank God I am away from her. (W12)*
>
> *I was talking to my mother back home in Somalia last week and she said, "Our neighbour is going to do this [FGM} on her daughter and I said to her, "Please tell her to wait for a week. I will go there next week and talk to her". My mum said, "Are you crazy? They already prepared everything and that's their business". I said, "No. You are crazy to make our life affected by this". (W12)*

Some women believed that it should be mandatory for each woman to inform other women in their community who are unaware of the legal and health consequences of FGM, for example:

> *For me as a woman, I always talk to other women and inform them that FGM is not good and talk about its negative impact in their private and social life. And what men are doing to women by controlling them. I provide more information to the community about FGM and what to do to stop it. (W15)*
>
> *Maybe some of the women don't know anything about the consequence of FGM. We need to give some awareness to the mums, what they need to do if they have the FGM, like step by step. Who they need to talk to, like a GP or midwife, like a guide. (W5)*

A few of the women reported that women accepted that their daughter should be circumcised due to their lack of social status, as explained here:

> *I know women who were forced by their husbands to send their daughters for circumcision. And when they resisted and tried to stop that happening on their daughters, the men wanted to divorce them, so they just accepted it. We have to work hard with women to educate them and empower them not to accept such a thing in any situation. (W20)*

Women saw that they had a critical community-based role in stopping the continuation of FGM. Many highlighted the role of women as mothers in shaping the attitudes of their children towards this cultural practice. They stated that if a woman is educated and empowered, she is unlikely to agree to such harmful practices, as explained here:

> *Every mother has a role to train her kids, regardless of whether they are boys or girls, on how bad is this FGM. And if I don't do it on my daughter, I am sure she will not do it on her daughter. I know with FGM they want to control girls to protect their virginity so they cannot go around and have sex with boys. And still many women themselves, in our community, they are looking for a girl who is circumcised to be married to their son. I mean it is not something that is only enforced by men; women themselves play a great role in the continuation of this practice by injecting this idea in their son's minds that girls with FGM are better and pure. We need to educate those women in the community. (W20)*

Women believed that just by sharing their stories of suffering and trauma as consequences of FGM, they would educate and empower the next generations of girls to say no to FGM. These mothers explained how she had spoken to their daughters:

> *I told my story to my daughter and told her that when I was young I got lots of problems because of FGM and I informed her that it is bad. I explained to her, her rights and freedom and I told her no one can touch your inside. Each woman has a responsibility to inform their children, for example I told my daughter and I am sure she will never do it because I told her she has the right and freedom to say no if someone wants to touch her body. (W9)*
>
> *You know, before I learn about FGM I thought, "Oh OK, I might do type one on my daughter but not type three but now after learning and talking to nurses and midwives I am not doing anything. ... We as women have to stop this at first point by telling everyone no to having FGM on ourselves and our daughters. In my family no one will do it again, either overseas or back home. (W12)*

Most of the woman believed that their voices would not reach the policy makers' level unless they joined a public conversation about this issue and shared their needs and insights in order to improve the situation for themselves and the next generations. They realised that they needed to stand up for their communities, for example:

> *And from our position, we women with FGM need to tell everything and raise our voices, otherwise no one will know what happened to us and no one will know what we need or want. And at the end it would be great if both sides - I mean government and women - come together and do something even better for the next generations to stop this practice. (W17)*
>
> *If the government doesn't know anything about all these problems and how affected women suffer how they can help us? We need to get our voice to them through advocacy and studies - like this one you're doing. (W10)*

Women noted that many women are ashamed and suffer in silence and saw this as a challenge to raising public awareness. Despite their personal shame, they believed that sharing their stories of suffering and trauma will be effective, even though they fear being socially ostracised by their families and communities if they express dissenting views. These women bravely explained:

> *I know our community would hate us if we openly say this practice is bad but if we are empowered and educated, we can raise our voice. I reckon in the next 10 or 20 years there will be no problem with this. We just need to be educated and empowered. (W23)*
>
> *You know, the problem we have here we [women] can't socialise and talk about this issue. We need to create an environment where people talk about it. You know it is very hard to disclose such issues at community level, as it is a very private matter. I guess if we bring up stories and how women are suffering this would be effective to change this culture in the future. Imagine you're living for someone else's pleasure and you're getting none. (W13)*

Women believed that community campaigns are important steps towards raising awareness. They realised that they needed to be able to speak out for themselves to obtain their rights. Providing simple and clear information to women from early ages through to adulthood was regarded as a way to improve women's confidence and knowledge about their bodies. This woman said:

> *The campaigns are great but beside of that they have to enable women speak for themselves and raise their voices and reject bad cultures. To empower women to that level we need to give them clear information and educate them about what is wrong or right and what are their rights…Sometime they are not confident about their bodies and they think they are shameful or that there's something wrong with them. I was exactly the same before but now I learned to be open and talk about my problem. (W14)*

This subtheme elaborated women's accounts on the importance of ending FGM by empowering themselves through education and taking a leadership role in their societies. Women believed that if they are truly empowered, they would be able to bring a change in the life of the future generation of women and girls.

8.2 Strengthening maternity care systems

Women with FGM reported needing to work together to strengthen the maternity system. This echoes statements made in the previous chapter. Participants expressed the need for all women to have special, comprehensive and comfortable services, in order to improve their emotional and physical well-being.

At a health service level, women wanted an acceptable level of culturally sensitive care, welcoming environment, with efficient access to all required resources. Their vision for improving the quality of maternity care centred on ensuring a reasonable allocation of workload for maternity care providers, and a well-trained workforce who are competent in the care of women who have undergone FGM.

Women talked about the need for increased availability of comprehensive or specific services and resources for women who are affected with FGM. They stated that these services should be provided in a kind yet efficient manner. The women recognised the importance of attending maternity care services that offered them specialised and comprehensive care in relation to FGM:

> *We need access to all medications and facilities. We should have our own midwife and specialist with all the information that we need. I want the health system to tell a woman what are her rights before she goes through birth. (W17)*
>
> *I want to give birth in a big hospital which has everything and departments designed to deal just with maternity issues, no other unrelated disease and cancer and infection - just specialised for maternity issues. (FGD3)*

Women also spoke of the need for mental health support and counselling services, both at facility and community levels, for example:

> *They should provide more special care for women with FGM, provide them with as much support as they can. Make sure they are OK, mentally and physically. Do the follow up afterwards. Education and individualised support not only for women who have undergone FGM but also to train staff and the community. It goes both ways. (W16)*
>
> *Individual counselling at hospital and also at schools would be so helpful to protect kids by speaking to them individually. Sometimes kids don't speak about these things. They need to train a special counsellor also because the usual counsellor doesn't know anything about this. Maybe someone from a similar cultural background. (FGD2)*

Women made several recommendations about emphasising the importance of individualising health information resources for women affected with FGM. During group discussions, women indicated that *giving the right information at the right time is crucial for women like us who are not highly educated. (FGD3)*

Women were concerned about the limited resources allocated to providing this information in Australia. They explained:

> *To me the most important thing was that they should give me the information I needed. In my country no one explained to me what was going on in my body and I expect that that shouldn't happen here. (W14)*
>
> *They gave me each time good advice, like stop this or that or eat this or that - you know all the information given to you during pregnancy. But no one talked to me about my FGM or caesarean as an option, no one. (W12)*

One woman, who is a community worker, was more positive. She described a change in the way that midwives are talking to women about FGM:

> *They never asked about FGM or gave me any information in my time but recently I witnessed that, from the beginning, the midwives talk about circumcision with women and some of the midwives they are really into their work. They even draw a picture to make it clear for women how they are going to open them. (W10)*

Many women perceived that most of the information they received during antenatal clinic visits were concerned with general birth preparedness and family planning. The following are some of the points they made:

> *They always pressured us with lots of information to avoid pregnancy [family planning] rather than paying attention to other things such as FGM. (W17)*
>
> *All the information they gave me was about exercise, and delivery, blood pressure just normal stuff they gave to everyone. I mean they consider us like other women without FGM. They don't have something special for us. Even they don't talk about it. (W7)*

Several women mentioned that they had found information about FGM from their family and friends rather than maternity care providers. They explained:

> *She [sister in-law] was so helpful. Lucky, I lived close to her and had got lots of information from this sister in law, otherwise in the hospital no one explained those things to me. (W14)*
>
> *You know, finally my husband gave me the answer to my questions. I was very upset that they didn't give me the information which is my right to know. (W22)*

Women recommended that funding should be made available for innovative ways of providing information to the community, such as the use of social media and mobile apps, for example, one woman said:

> *And make sure when you give information to the communities, they understand it. Believe me they don't understand or read any of those flyers or pamphlets. We need new, innovative ways to give the information through phone or like, videos, billboards, social media, pictures around the community et cetera. (W15)*

A few women requested audio-visual information in the form of video. This was because they found it difficult to understand all the materials as they were not in their own language and there were lots of resources provided by the health services that were overwhelming. Two women said:

> *Also, they should have to show us some videos rather than give us information in the paper form. I personally may not read it or if I read it because it is too much and not in my language, so I don't remember it again but when it is visual you always remember it. (W20)*
>
> *They never give us information about FGM when we go to the hospital. It would be good to provide us some pictures or videos and show us what will happen to us during birth with our circumcision. (W21)*

Based on their specific needs, women felt it was crucial to provide timely and proper information in order to protect girls from FGM. For instance, one woman said:

> *I had a baby girl and I could have taken her for FGM but they have educated me and given me required information that I should not do that. ... Midwives need to talk to them, give them information about how bad it is and explain the law. (W17)*

Women also emphasised that women giving birth for the first time might have a specific need to learn about basic health information. They shared their experiences of receiving resources that were tailored to their needs:

> *Especially those women with first pregnancies, they need to guide them about where to go and from whom they should ask for help and always talk about their issues related to FGM. (FGD2)*

8.3 Increasing government support

Women considered government support as critical to improving maternity services and prioritising the health of women affected with FGM. Government support was considered as a cross-cutting issue which is linked to all future actions and approaches. Women used the word government to mean all high-level decisions, policy and funding at local, state and territory and federal levels. They wanted resources to be made available for improving the health of affected women, introducing FGM as a topic in the school curriculum and making meaningful linkages with communities. They believed such strategies would ultimately lead to the improvement of the health of women with FGM and society as a whole.

> *They [policy makers] need to identify women with FGM as a priority at policy level and provide them with things they want. We want services which all women deserve not more. We are in a developed country and we should have access to standard care from an experienced health provider. (W21)*

Women constantly expressed the idea that, as they were part of Australian society, public services need to be aware of their needs and support them closely. They described future actions and successful implementation of community-based projects where services and communities engage as a team, in activities to improve the health of women with FGM.

> *Government, community and health providers should work together and understand each other's culture. The Australian government should be aware of our needs then they can plan accordingly through knowing about the problem. Our role as women is to raise our voice and hold it at a higher level so they can listen to us. (W10)*

Most of the women believed that there is a lack of connection and linkage between governments and communities, which makes it hard to communicate communities' problems to governments. One woman explained:

> *There is no connection and communication between the community and the government at the moment. They should do more study on communities and their needs. More hospitals and information sessions for the community. (FGD3)*

Several women articulated the value of research about communities' needs and perceived research as an effective way to be heard at the policy level, for example:

> *The government should consider FGM as an important health agenda, to look after women with FGM. We need to advocate at a higher level, for example, this research you are doing shouldn't be just a research for you, it should go to other levels. It shouldn't be written in a paper it needs to be considered for future action also. (W2)*

Women expressed appreciation of this study stating that it gave them a voice. They said things like:

> *This type of work you do is a good way to get our voice to government. They need to know we need more nurses and midwives with special training in FGM. I reckon we need more research and information in this area to present to a higher level for their action. (W10)*

> *If the government don’t have time to talk to us and I as community member don’t know how to transfer my voice to you then the problem will be there forever. They need to have more researchers who listen to our voice like you. (FGD3)*

One woman stated that there are still religious leaders in the community who support the practice of FGM. She suggested that the government needs to identify key actors and groups within communities, build a relationship with them, and start to work with them in partnership to get engaged and educated about FGM:

> *The government has to convince the community that this is bad. Still many people in the community believe it is a good thing to do on their daughters. We can ask women to share their stories with members of the community as examples. They should work on religious leaders in the community; some of them are promoting the FGM through their preaching. I remember once they quoted a Haith that says something about FGM like, Even if a man and woman get together illegally they should be both cut'. I think type one is our ‘Sunnat’ and is not bad but the type two and three are bad. Train the community, put it in the media and enforce the law. (W22)*

Women observed that governments can bring men and women together and start an open discussion with them. One example of this is outlined here:

> *The government needs to talk to communities purposefully on this matter, both women and men. The government can empower women by more education and community awareness. Some women and men in the community can’t say the term and have no idea what FGM is so I guess governments have a lot to do on this. Somali men they don’t want to talk about these things. (W12)*

Women also suggested that governments can facilitate a series of community-based forums to raise awareness and open debate in the community about this practice:

> *You know there are two groups in the community - one group who don’t*

> *know anything about it (FGM) at all, and there is the other group who went through it and have experienced all the pain. The government need to do something so that the two groups can come together and talk about it openly. (W13)*
>
> *If the government don't talk to us and we don't talk to them, nothing is going to change. The government needs to create a space for us to talk to them. Through facilitating and funding community training, such as workshops for men and women, we can raise awareness. It is also helpful to open the discussion around this issue; at the moment it is not culturally appropriate to even talk about it. (W20)*

Women in this study wanted governments to initiate programs for promoting women's health within the community to support them in improving health outcomes for women with FGM. Recognition of the needs of different cultural groups would be crucial in any such programs:

> *The government has a big role. This is a multicultural country; there are different people from different cultures from around the world here, so people and governments, both should be educated about these things. Do research about them if you don't know. Because, if a country accepts people from overseas, they should do more research about them. We are living here now; this is our home and we have to be treated as everyone else. (W2)*
>
> *The government should do more study so they know everything and make it better for us and how to deal with women who have been cut. They can ask women what they want and feel or how they can help us. I know these dreams may not come through for us but for others it should be better. I mean you need to bring all these issues by research out and present it to the government so they can solve it. (W17)*

Women believed that much work needs to be done to inform communities, including youth, women, men and health workers about women's health and rights. This was highlighted here:

> *Because in my country there is no education about these issues and people who are coming here, they have no knowledge about FGM. All they know they should follow the culture and religion and it passes on and on generation by generation even here. That's why the tradition still hasn't changed. So, with educating people we can change this in long term. (W13)*

Women pointed to cultural taboos, which makes it challenging to have open discussions about FGM with male members of the family. The training opportunities to be funded for them and their children to learn about those issues. A number of women made suggestions like these:

> *I wish school had some sort of training about this for boys and girls. It is so hard for me to talk to my son about FGM. I know it is not good. I need ideas on how to explain this to my son really. (FGD3)*
>
> *Facilitating and funding community training such as workshops for men and women we can raise the awareness. It is also helpful to open the discussion around this issue. At the moment it is not culturally appropriate to even talk about it even in the family. (W20)*

Allocating resources for primary and secondary school education about FGM was suggested by the majority of the women, however some women wanted the training to be inclusive of all cultural backgrounds rather than just those people from Africa. For example:

> *I wish all the schools, besides other programs, they also add a topic on FGM and orient kids on all the side effects of this practice. Schools are multicultural and they are the best place to teach our kids about different cultures and bad and good things about them. It shouldn't be just for African kids it should be for all. Many of these kids might have ended up becoming a doctor or nurse or many of the kids might end up to be a victim of this practice and both groups will benefit if such topics are raised in the school. And beside they have to teach kids how they can protect themselves by giving*

> *them all contacts and access for help and support. (W20)*

> *...put this topic in the curriculum of the schools. So, our teenage kids can learn about it. Most of our girls by 18 get married and get pregnant. ...to me even not just at high school it should start from primary level. Our kids need to understand that no one should harm their body. They usually take kids at primary level away during summer and cut them. (FGD2)*

The importance of providing funds by government for FGM specialised clinics and training of the community was emphasised by most of the women. For example

> *I think there should be resources available to women who have been cut. I don't know maybe like special clinics to serve them because especially for my Indonesian community they don't think it is a big deal and it is already very common. So we [women] don't know really the effect of that. Maybe the government can provide a course to the patient who have this and through that course the patients should talk to the rest of the community. (W8)*

One woman suggested that the establishment of a reporting system at community level is important in order to stop the practice. She explained:

> *There should be an information and reporting system within the community or sessions for women and men who are going back home to do this practice on their daughters. Because I know some of those women who still go home to do this on their family members and no one reports it. (W2)*

Summary

When women were asked how they thought they could make their dreams a reality in relation to improving maternity services in relation to FGM they suggested a range of strategies. These were grouped into the themes representing three levels of action: mobilising and enabling communities including men, strengthening maternity care systems and increasing government support.

Participants highlighted the importance of community mobilisation to plan and implement change to prevent FGM and better care for affected women and girls. Women described the need to raise community awareness through education and media campaigns involving women, men and youth.

Women described feeling empowered when they shared their stories and regarded these as an important resource for mutual support and to educate the community and challenge cultural beliefs about FGM. Women drew on these stories and experiences to identify ways to strengthen maternity care systems so that they might better address the needs of women with FGM.

Women made recommendations to improve government funding for health information resources regarding FGM and maternity services in Australia. They also identified the need for funding to address the education of maternity care providers to develop competent clinical services for women with FGM.

Chapter 9: Discussion

Introduction

This qualitative study aimed to provide knowledge about the maternity care experiences and needs of Australian migrant women who have undergone FGM, to improve the quality of maternity care. In total twenty three semi-structured individual interviews and three focus group discussions were conducted. All women were affected by FGM and had received maternity care in Australia. An Appreciative Inquiry methodology was applied to make sense of the women's experiences and collaboratively develop strategies to improve services.

The six specific research questions that guided this study were:

1. What do women affected by FGM perceive as quality maternity care?
2. How do women with FGM feel that their culture is acknowledged by maternity care services and how could this be improved from the perspective of cultural safety?
3. How do the relationships that women affected by FGM have with obstetricians, midwives and other health professionals during pregnancy and after birth impact on quality care?
4. How have women with FGM experienced maternity care decision-making and how do women think decision-making could be improved?
5. What expectations do women with FGM have of maternity health services in Australia and were they satisfied with the care they received?

6. How can women with FGM be more involved in the co-production of maternity care, services and information?

The findings were presented under five themes, four of which were aligned with the ‘4Ds’ cycle of Appreciative Inquiry: ‘Appreciating the positives in their maternity care’ (Discovering), ‘Desiring the best in maternity services’ (Dreaming), ‘Planning together for improved maternity services’ (Designing), ‘Improving and sustaining’ (Developing/Deploying). The remaining theme was ‘My FGM story’. Each theme is supported by sub-themes that emerged from an inductive and deductive analysis of the women’s experiences to uncover shared meanings of being circumcised and using maternity services in the different context and culture of Australia (Figure 5).

This research identified a range of positive findings that illustrate women’s views about quality maternity care. However, women acknowledged that the maternity care they received had not always been at the level of quality that they desired or had expected. One of the key findings was that women felt that they had not been engaged in all aspects of their care. In line with the systematic review I conducted as part of this study (Turkmani, Homer & Dawson 2018), women reported that being meaningfully involved in their care design and delivery was a crucial strategy for building trust and improving and validating the quality of maternity services. Women often felt that they lacked access to basic human rights such as having control over their health care, access to shared decision-making and adequate information to enable informed choices. While most women were motivated to be involved in their care, they struggled with poor communication and a lack of information tailored to their individual needs. Women wanted to be cared for by skilled and culturally competent providers who treated them as ‘special’ but also as normal and equal to ‘other women’. Finally, women described the importance of having access to evidence-based models of care such as continuity of care and available services including, reconstructive surgery, management of trauma, emotional support, psychotherapy services and cultural support.

Designing a conceptual framework

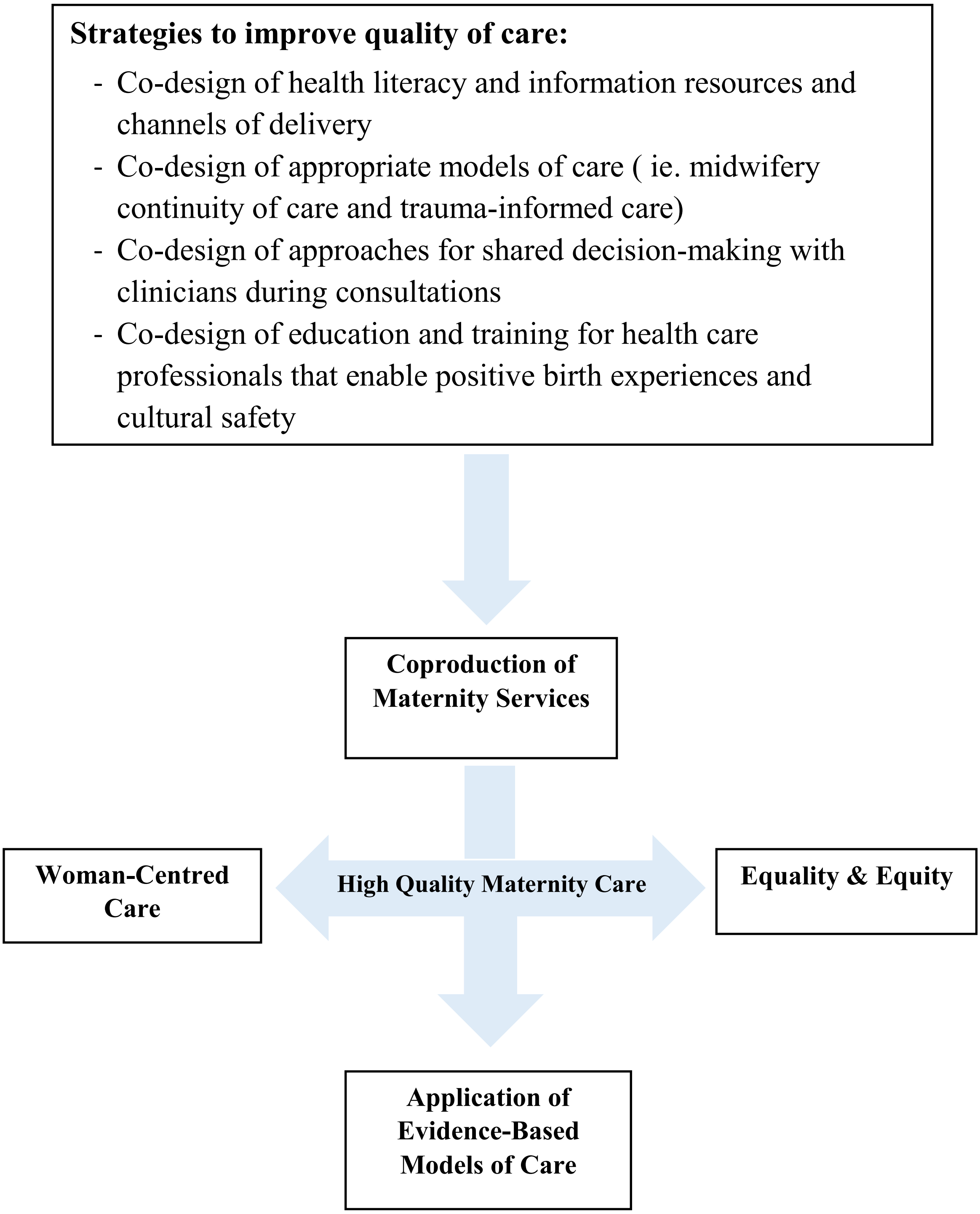
The analysis of women's responses involved an interpretive process that highlighted the importance of involving women in the design and delivery of their care. I developed a conceptual framework to highlight four priority strategies that are based upon women's experiences and needs as revealed in the research findings of this research. The framework elaborates the areas of women's engagement and involvement in developing health information and being an equal partner in the co-design of maternity services (figure 6). These co-design strategies can be applied to improve the quality of maternity care. This is consistent with other research that describes 'Experienced Based Co-Design' (EBCD). EBCD includes: collecting experiences, understanding experiences, identifying gaps and problems in a collaborative way, following up and acting for improvement (Bate & Robert 2006).

The knowledge produced through this evidence-based framework should be synthesised in the future and included in technical guidelines, future intervention plans or clinical practice. Further research is needed to explore the feasibility and replicability of this conceptual framework and its effectiveness in terms of improving quality of care and equitable health outcomes.

The next sections present details of the conceptual framework with examples from my research findings and in relation to the literature under the four priority strategies. These are: 'Co-design of health literacy and information resources and channels of delivery', 'Co-design of models of maternity care', 'Co-design of approaches for shared decision-making with clinicians during consultations' and 'Co-design of education and training for health care professionals' (Figure 6).

At the conclusion of this chapter, I will outline the strengths and limitations of this study along with implications for practice and future recommendations related to the improvement of quality of care for women affected by FGM.

Figure 6: Conceptual model of quality improvement within maternity services for women with FGM



Strategies to improve quality of care:

- Co-design of health literacy and information resources and channels of delivery
- Co-design of appropriate models of care (ie. midwifery continuity of care and trauma-informed care)
- Co-design of approaches for shared decision-making with clinicians during consultations
- Co-design of education and training for health care professionals that enable positive birth experiences and cultural safety

Co-design of health literacy and information

In my study, women regularly described the need for information that is tailored to their individual needs. Women noted that support services, such as counselling, were not always accessible due to language and cultural barriers. Some women stated that these services were not available or integrated into maternity care. Other studies in HICs have found that women affected by FGM do not always receive or understand the information and resources they received or needed because of social isolation, stigma and a lack of health literacy (Davies & Bath 2001; Turkmani, Homer & Dawson 2018). Improving the health literacy of women with FGM may change the attitudes of women towards FGM and reduce the likelihood of their daughters being circumcised (Alo & Gbadebo 2011). According to the WHO (2009), if health literacy contents are understandable and culturally acceptable, individuals would be able to gain better social skills and build enthusiasm in order to access services and use information in ways which promote and maintain good health. Women have the right to appropriate information at the right time, and to knowledge of the risks and benefits of all health care options (UN 2016).

Every woman should feel empowered to build her capacity and skills to use health information effectively and make an informed choice (Asekun-Olarinmoye & Amusan 2008; Kickbusch 2001). However, many women in my study stated that they were not adequately engaged in their health care because of low levels of health literacy, inadequate information and unfamiliarity with their health rights. These findings concur with other studies that showed women did not feel safe to ask for information or engage in their care due to the superiority of health providers (Ebert et al. 2014; Origlia et al. 2017). My research suggests that if women are engaged in the process of designing health information, they are likely to improve their understanding of health issues and health care services thereby develop a sense of responsibility for their own care and trust in the health system.

The level of women's engagement in their health care appears to have a direct link with quality improvement. Other studies confirm that women's participation in the process of health information design leads to more satisfying and positive experiences with enhanced health outcomes (Svensson, Carlzén & Agardh 2017). When women have lower levels of health literacy, they are less prepared to engage and comply with their care regimes or protocols and as a result do not receive optimum care (Gustavsson, Gremyr & Kenne 2015). For instance, women with poor health literacy might not disclose their health issues to health professionals antenatally and could present during labour and birth with undiagnosed conditions (such as FGM, as reported by women in my study). This lack of disclosure of predisposing health conditions may contribute to an emergency situation that could have been preventable, requiring interventions some of which may have been unnecessary (Higginbottom et al. 2014). Similarly, poor levels of health literacy may lead to unrealistic expectations on the part of women, such as requests for unnecessary interventions, medicines or services which do not apply to their condition (Beckett et al. 2014). Tasi et al. (2014) and Wills (2009) noted that poor health literacy due to inadequate health information can lead to risky behaviours such as a delay in seeking help or avoiding health care due to misunderstandings and fear. In addition, marginalised populations, such as migrants or refugees, have numerous challenges associated with settlement as well as coping with stigma, language difficulties, cultural and socio-economic barriers. Therefore having appropriate health information might not be a priority for them (Asgary & Segar 2011; Chuah et al. 2018).

Little is known about the effectiveness of existing FGM-related health information or other relevant health literacy interventions (Smith & Stein 2017). However, community-based participatory health literacy programs increased the likelihood of collective changes in the attitudes of society that could lead to the prevention of FGM (Waigwa et al. 2018). Woodland et al. (2010) and Chen and Quiazon (2014a) have highlighted the importance of engaging disadvantaged populations through informative communication and dialogue to ensure access to health information and available services. Similar to my study findings, Chege et al. (2004) indicated that the involvement of key actors in the community such as religious leaders and men in the process of FGM health education can bring positive behaviour change. Therefore, direct inputs from target populations can ensure health information is tailored to the unique needs and circumstances of women (Dawson, Turkmani, Fray, et al. 2015; Turkmani, Homer & Dawson 2018). One study, among Somali pregnant women, revealed that they were often supplied with excessive unrelated or culturally unacceptable information rather than individualised or relevant information (Davies & Bath 2001). A study in the US stressed the lack of effectiveness of health literacy programs for affected women due to the language barriers (Jacoby et al. 2015). Sometimes, health providers during pregnancy and childbirth gave information based on their own personal assumptions regarding women's needs rather than involving women in active ways to understand their needs (Levy 2006; McKenzie 2004). Health information that meets women's needs and is consistently evaluated and modified with women's direct involvement will help them to make informed choices and have control over the decisions they make (Levy 2006).

Greater engagement of women in the process of developing health information and education materials may improve a woman's confidence to communicate her needs more effectively and thus improve health outcomes (Batterham et al. 2016). Other research has shown that women do not always trust information from health care providers due to poor experiences with health professionals, or the poor experiences of their peers (Chen & Quiazon 2014a). Similar to the findings of my study, there is evidence that women can be stigmatised by poor attitudes of health providers. Women may also mistrust or fear providers due to the illegal nature of FGM and are therefore reluctant to disclose their FGM status (Burnett & Ndovi 2018; Reisel & Creighton 2015). As my findings show, women also report being frustrated by the lack of time allocated for them to spend with a health provider and feel that it may negatively influence effective communication. This may lead to a lack of time to initiate a conversation concerning their individual needs and affect a woman's ability to build rapport with her provider, who is also limited in his/her ability to assess and understand the woman's concerns (DeRosa & Stribling 2018). However, many of the women in my study initially sought FGM-related health information from other sources such as peers or family members. The information women received from other sources, such as friends and relatives, were often stories and experiences involving a mistrust of health care providers and the health system that may have had a negative influence on women's health-seeking behaviours.

Evidence recommends that health information should be readily accessible especially for populations with low literacy and it is necessary to develop the formats of such resources in direct partnership with service users (Ramsay et al. 2017). Where women are engaged and can share their experiences with their peers, community health literacy improves (Campbell & MacPhail 2002). An evaluation of a program in Canada that employed a women-centred framework, found that direct interactions of women with their peers to share informal health stories rather than a formal education by a health provider enabled them to trust the information they received and recall it more quickly and put this into practice (Barnett 2000). In a recent study in the UK, peer education also empowered women to transfer their knowledge and experiences with confidence to their peers without being influenced or judged by others (Fisher & Fisher 2018). Such health literacy models offer women a safe space to share FGM-related experiences and to address issues themselves (Chen & Quiazon 2014a; UNPFA 2005). Health literacy programs that involve women designing and delivering programs not only build the capacity of women to facilitate sharing stories and experiences, but also empowers women to support others in their community (Manderson & Allotey 2003).

Involving service users in the design of health education has been successful in many areas of health prevention including the prevention of: drug use (Ward, Hunter & Power 1997; Wills 2009); HIV (Campbell & MacPhail 2002); sexually transmitted infections (Sarafian 2012); violence against women (Davies 2007); and diabetes (Ogrin et al. 2018). The findings of my study also suggest the use of community-based participatory health education and promotion through storytelling would improve the health literacy of women with FGM, as found in other studies (Chen & Quiazon 2014a). Involving women in the development of information and educational material has resulted in resources that are relevant and culturally sensitive (Caplan & Cordero 2015). This approach to designing health education should be formally recognised by the health system and supported in maternal health programming (Chen & Quiazon 2014a).

Different levels of community engagement in the design and delivery of health promotion materials are well documented in the literature. Caplan and Cordero (2015), for example, introduced a mental health literacy intervention to produce health information based on the cultural and contextual needs of the Latino community in the US, who often sought health information from religious leaders. The active involvement of Latino community members and religious leaders in the development of the health literacy program in this project was key to overcoming inequalities in access to specialised mental health services and delivery of culturally appropriate interventions for socio-cultural stigmatised groups (Caplan & Cordero 2015). Similarly, another study showed that involving the community in the development of health promotion materials that incorporated familiar and contextually relevant infographics enhanced the engagement of individuals in the program, motivating them to change their behaviour. For example in this study, patient involvement improved women's comprehension of their own health care data and enabled them to communicate their self-management outcomes to health providers (Arcia et al. 2016). Another study that involved people with diabetes in the co-design and development of a health promotion software application for the prevention of diabetes, found that co-designed materials were perceived as more user-friendly, practical and acceptable by the users and improved community awareness about diabetes (Ogrin et al. 2018).

In summary, my study showed that low health literacy among women can lead to poor health communication, a lack of awareness of the care process and a lack of service utilisation. The engagement of individuals and communities is critical to the process of improving the quality of health services. Empowering women and raising their awareness of their health care rights can help to engage women as active partners in the design and delivery of health information, which is based on their needs and context.

Co-design of models of care

It is imperative for the health system to be based upon an understanding of women's perspectives and their health needs so that the best model of care can be provided. My study found that women who experienced FGM-related trauma appreciated continuous care. Therefore, two important issues to be addressed in provision of quality maternity care for women with FGM are: ‘trauma-informed care’ and ‘midwifery continuity of care’.

Trauma-informed care

Most women in my study reported different types of FGM-related trauma, which affected their overall quality of life. The central philosophy that underpins high-quality maternity care is not only a focus on physical health but also emotional well-being, including quality of life issues (Renfrew et al. 2014). In my study, women perceived high-quality maternity care as much more than the provision of clinical services. Women expected health care providers to be responsive to their psychological, emotional and socio-cultural needs as found in other studies (Mattern, Lohmann & Ayerle 2017). Despite the emotional and mental consequences of FGM, most other studies are focused on the physical aspects and implications (Andro, Cambois & Lesclingand 2014; Vloeberghs et al. 2012). Laio et al. (2013) indicated that women affected by FGM are often silent about their emotional problems due to the stigma associated with FGM and have difficulty communicating with health providers. Therefore it is difficult for care providers to recognise or determine the level of psychological trauma that may be caused by FGM and that requires a health care response. Women in my study not only recognised the impact of their childhood trauma but they also emphasised the need for the provision of appropriate trauma-informed care addressing their emotional needs. However, management of trauma was most often missing in these women’s maternity care plans, mainly because women were reluctant to communicate their issues or because providers did not ask them. Evidence also showed these women are less likely to report or disclose their psychological concerns and mental health needs with regard to FGM-related trauma due to stigma and fear of being condemned by health professionals (Andro, Cambois & Lesclingand 2014). Many of the women affected by FGM may have no access to mental health support services and may be unfamiliar with the services available to them (Liao et al. 2013).

Women in general are at greater risk of psychological disorders such as depression, anxiety and traumatic distress during pregnancy and after birth (Altshuler, Hendrick & Cohen 2000; Nillni et al. 2018). A case control study, for instance, estimated the prevalence of anxiety disorder during the perinatal period to be about 18% (Uguz et al. 2019) and about 9.2% of women experience a depressive disorder during pregnancy and postpartum (Falah-Hassani, Shiri & Dennis 2016). Therefore, considering the magnitude of mental health issues during and after pregnancy, a universal precaution for trauma is advisable for every pregnant woman who is seeking health care (Raja et al. 2015). Psychologists have emphasised that when an individual is unable to verbally express their traumatic experience, physical symptoms can ensue, such as cardiovascular, respiratory and neurological diseases (McFarlane et al. 1994; van der Kolk 1994). Providing a safe space for women to disclose their trauma and for a collaborative discussion to be initiated between a woman and her provider is therefore an important step towards addressing trauma (Bath 2008).

Evidence indicates that sometimes the complexity of trauma, such as FGM, could lead women to adapt adverse health behaviours (Reeves 2015). Similarly, Sullivan et al. (2018) indicate that women may utilise different strategies in order to cope with their anxiety and mental issues and in order to avoid re-traumatisation. For instance, FGM-related mental health issues such as PTSD, negative body image and feelings of shame and stigma may affect women's health seeking behaviour, as agreed by other evidence (Andu et al. 2018; Caillet et al. 2018). FGM-affected women may avoid their regular antenatal visits despite their problems during pregnancy, which may result in complications and poor outcomes for themselves and their babies, as indicated by other studies (Berggren, Bergstrom & Edberg 2006; Vloeberghs et al. 2012). There is evidence showing a correlation between negative emotions and experiences during procedures such as vaginal examinations during labour, and FGM-affected women's anxiety, stress and pain due to past traumatic experiences (Asma, Trister & Nicole 2018).

In my study, some women who were dissatisfied with their sex life, indicating that they would like to have been offered counselling for themselves and their partners. Some women developed a negative genital body image after de-infibulation and felt uncomfortable, and many wanted re-infibulation. However, some felt pressure from their partner to be re-infibulated that concurs with other research (Caillet et al. 2018). These kinds of FGM-related trauma are important because of their implications for childbirth and sexual relationships highlighting the need for individualised trauma-informed interventions for such vulnerable women. A trauma-informed model of care is the way to support and provide safe care to women who are affected by violence and ultimately reduce the consequences of trauma in their lives (Shaw et al. 2016).

Trauma-informed care is an approach that incorporates a clear understanding of the impact of victimisation and trauma in a woman's life. Health care providers are trained to work collaboratively with women and provide them with unique support and referral (Elliott et al. 2005). Trauma-informed models of care have been successfully incorporated into mental health services in the last two decades. For example, an integrated trauma-informed approach has been utilised as a part of the treatment plan for addressing the mental health effects in the event of domestic violence or drug and alcohol abuse (Mihelicova, Brown & Shuman 2018; Wilson, Fauci & Goodman 2015). A trauma-informed model of care for pregnant women with FGM is in line with WHO's (2016a) FGM guidelines that recommend psychological support services for women with symptoms or experiences of trauma and mental disorder. A tailored approach is also important because trauma may have an invisible impact on women and each individual may react differently to their traumatic experiences (Covington 2008).

Midwives are the main care providers for pregnant women and, as a result, have the most contact with women during their pregnancy and childbirth. Midwives can provide emotional support to women during these times, including trauma management, which is an essential aspect of a psychologically positive birthing experience for women (Malacrida & Boulton 2012; Renfrew et al. 2014). In the context of FGM, a trauma-informed care approach requires midwives to investigate the history of FGM for each woman in order to understand the mental impact of such trauma, provide a collaborative evidence-based care plan and be self-aware of interpersonal communications with women (Asma, Trister & Nicole 2018).

Delivering trauma-informed care, however, may require changes to health service delivery to ensure an enabling environment. Power relations in service delivery need to be carefully considered and strategies enacted to reduce these, such as woman-centred advocacy, shared decision-making and empathy (Kulkarni 2019). Similar to the findings of my study, evidence suggests that women should be involved in the design of trauma-informed services so that individual needs, views and experiences can be addressed in a collaborative way (Asma, Trister & Nicole 2018; Sandall et al. 2016). Efforts in the area of trauma-informed care currently focus on strengthening health providers' knowledge and skills based on their interactions with consumers, rather than understanding a woman's experiences and needs (Kliewer et al. 2004; Wilson, Fauci & Goodman 2015) that need to be integrated into maternity service design (Kulkarni 2019).

Evaluations of efforts to integrate trauma-informed care into services for vulnerable populations, such as people with mental disorders, histories of drug abuse or sexual abuse and violence, suggest expanding the role of service users, in particular their involvement in the design, development and delivery of these services (Kulkarni 2019; Wilson, Fauci & Goodman 2015). Improving providers' clinical skills to deliver trauma-informed care is necessary for quality care. However, women need to be actively engaged in their care to ensure improved health outcomes (Hales et al. 2019). For instance, women can be involved in building providers' skills by serving as co-trainers during health providers' in-service training, or they could participate in service evaluation teams or advisory committees (Elliott et al. 2005; Mihelicova, Brown & Shuman 2018).

Implementing participatory interventions, however, requires both health system and community change (Mihelicova, Brown & Shuman 2018). Women need to be supported to become empowered, to recognise their potential and utilise their capacity in the design and delivery of services (Castro et al. 2018; Hales et al. 2019). Creating an environment of collaboration and mutual trust by engaging women and acknowledging their values and lived experiences may ensure that women's needs are understood and their views and culture are taken into account in service design, thereby improving the quality of culturally safe care.

My study recognises that the implementation of such interventions requires a paradigm shift within many health systems that would involve all levels of leadership, extensive training of health providers and the allocation of adequate resources. The ultimate goal of such trauma-informed care in the context of maternity services for women affected by FGM is to not only support the survivors but also include them in the process of service design to create a foundation for shared action that is responsive to the needs of affected women and health providers.

Provision of midwifery continuity of care

Women in my study saw the provision of midwifery continuity of care as the core of maternity services and a crucial concept for building trust, equality and greater efficiency of services. Some women reported a lack of consistency in midwifery care and desired more postnatal visits. Women desired psychological support to cope with physical changes and sexual issues after de-infibulation and wished for this to be continued beyond the postnatal period. Women wanted this support to be delivered by a health professional who is already familiar with their health background and known to them. Pregnant women are more likely to trust the provider and share their cultural and health needs if they receive care from a known midwife over time (Sandall et al. 2010). Evidence shows that a continuum of care during pregnancy and postnatal can reduce maternal mortality and morbidity, prevent complications thus decreasing the chance of interventions, and improve a woman's sense of control and satisfaction with her care (Sandall et al. 2016). Continuity of care, in general, leads to improved interpersonal communication and can boost women's confidence, enhance collaboration between a woman and her provider, and help facilitate positive care experiences (Dahlberg & Aune 2013). Midwife led continuity of care however, enables health providers to consider the socio-cultural needs of a minority of marginalised women and therefore empowers women to achieve positive outcomes (WHO 2018c). Women who have received such continuity of care are able to collaborate effectively and express their emotional and physical needs (Dahlberg & Aune 2013). Spending time listening to the experiences of women would provide an opportunity for health providers to understand each woman's perspective and the factors that negatively affect her health (Bohren et al. 2017; Mercer & Reynolds 2002). It is important for women to develop positive relationships and rapport with their health providers through continuous contact at health facilities or at home to ensure that their values are embedded in the health services they receive.

Freeman et al. (2003) defined continuity of care as the meaningful integration of the patient's view into the process of care resulting in collaboration between the health provider and the service user. Establishing a trusting relationship and woman-centredness are fundamental parts of continuity of care (Freeman et al. 2001).

The three commonly cited models of continuity include 'informational continuity' which links service users' personal data and health providers' knowledge over time; 'management continuity' to deliver responsive and timely services; and 'interpersonal continuity' that provides ongoing and consistent relations between health providers, women and families (Haggerty et al. 2003; Reid, Haggerty & McKendry 2002). Regardless of the context and discipline, all these models of continuity contribute to quality improvement of care and a woman's positive care experience (Dahlberg & Aune 2013; Haggerty et al. 2003). Women in my study sought midwifery continuity of care, although the women did not use the exact terminology. Women who had experienced any form of continuity of care reported feeling satisfied with this care and noted that it had been tailored to their individual needs and that they had had no difficulties communicating with providers. In contrast, some women expressed a need to prevent repeating their medical history to a different provider at each visit. Women also sought consistency in the management of their health issues rather than multiple opinions provided on their treatment or care plan from different health professionals at each visit.

While women in my study wished to establish ongoing and trusting relationships with a known health provider over time, they also expressed the desire to have a choice of having a midwife as their care provider. The findings of a study in Germany showed that while women had the option to choose their maternity providers during antenatal and postnatal care, the hospital allocated them an unfamiliar midwife during labour and birth. The women found this challenging, especially those from disadvantaged groups who had low literacy levels and difficulties communicating effectively (Mattern, Lohmann & Ayerle 2017). The findings of my study show that the characteristic of continuity of care that women valued most was building a close relationship with providers so that they can develop the emotional confidence and trust to speak out and share their stories and concerns without fear of being judged or blamed. The findings of other studies from Norway and Australia confirmed that developing relational continuity with health providers promotes women's engagement with their care (Dahlberg & Aune 2013; Riggs et al. 2012).

Midwife-led continuity of care during pregnancy, childbirth and postnatally with adequate visits is an important part of a package of quality maternity care services. The WHO recommends that full implementation of such a package of care requires standardised midwifery services, efficient operational management and advanced health workforce planning (WHO 2018b). Australia is known for its innovative maternity care system that offers women different models of maternity care (Donnolley et al. 2019). Midwife-led continuity of care such as midwifery teams, midwifery group practice, and shared midwifery care are commonly utilised in Australia and all of these models aim to ensure care is provided by the same midwife or a group of known midwives who promote positive experiences and increase women's confidence and trust (Donnolley et al. 2019; Homer, Brodie & Leap 2019). Women in my study seemed to be unaware of these models of care. Such models may not have been available to them and many believed that they did not receive continuity of care.

Continuity of care in itself is necessary, but not enough, to achieve high-quality care and must be combined with multi-dimensional evidence-based interventions (Guthrie 2008). Correa-Velez and Ryan (2012) emphasise the necessity of specific models of maternity care for marginalised and high-risk women, such as women with FGM, that encompass continuity of care plus educational interventions and the delivery of mental health support. Delivering continuity of care to a vulnerable group of women requires a clear understanding of the inter-relationship of vulnerabilities and socio-cultural factors. Women's experiences of continuity of care might be different based on their personal circumstances, and the context they are in. Therefore research has shown that health system and health providers need to understand and be mindful of those differences and influential factors by recognising their needs (Parker, Corden & Heaton 2011). The findings of my study suggest that the health system needs to work in partnership with communities and women who have specific conditions and understand the cultural and individual needs concerning continuity of care. Evidence shows that the continuous assessment and evaluation of women's experiences, opinions and views can be incorporated in co-designed approaches that can improve the quality of care for marginalised groups (Green 2012; Hackett, Mulvale & Miatello 2018).

Co-designing approaches for shared decision-making and informed choice

The findings of my study indicate that many women did not feel that they fully participated in decisions about their own care. Women regarded family involvement in decision-making as important as their own involvement in decision-making as it aligned with their cultural values. Women's accounts also showed that when family members were involved in decision-making, women felt safe and were re-assured that they had made the right decision. Research by Parker et al. (2011) found that the participation of relatives and carers in interactions with health care providers improves patient satisfaction and can influence compliance and continuity of care. For example, relatives and carers can assist women with their appointments or support women to learn and share health information. Such interactions can motivate a woman's partner to become more involved in supporting her to adapt to life in a new context (DeSouza 2006). Women in my study were eager to take part in their own care planning and decision-making and believed that having prior health information was a pre-requisite for such involvement. Women wanted their partners to be part of their care, as they could provide emotional support and assist with English language challenges. However, some women felt that they and their family had few opportunities to become involved and that decisions were largely made by health providers. This is discussed in other research that shows that those with lower levels of health literacy are provided with inadequate information and this prevents women and their families from taking part in decision-making processes (Ebert et al. 2014). When women feel empowered to be part of their care plan design, they are more likely to experience a physiologic birth with positive outcomes and less medical interventions for mother and babies (Ameresekere et al. 2011; DeSouza 2006). A woman-centred model of care provides disadvantaged women with a safe space and common ground to be able to make their own choices. In my study, women acknowledged their lack of health knowledge and wanted care providers to guide them towards rational, evidence-based and safe decisions and support them to be more aware of the risks or benefits of their decision, rather than dictating what they should do. If a woman understands the concept and the philosophy upon which her maternity care is based she is more likely to collaborate, enabling informed decisions to be made (Fontein-Kuipers et al. 2019). Socially disadvantaged women with poor levels of health literacy have been found to be excluded from decision-making and dominated by midwives and other health care providers' traditional power relations (Ebert et al. 2014; McColl-Kennedy et al. 2012).

A woman-centred approach

In Australia, the National Maternity Services Plan (AHMAC, 2011b) defines woman-centred care as:

> *'Care that is responsive to women's needs and preferences and enables them to access objective, evidence-based information that supports informed choices about their maternity care'. (AHMAC 2011, p. 25)*

The Australian National Health and Hospital Reform Commission called for person-centred care to be at the core of future health service design (National Health and Hospitals Reform Commission 2009). Women in my study perceived their maternity care to be of good quality if they could maintain a sense of control and if they had the power to express their individual needs and, as a result, receive the care they desired. Other studies have found similar findings to my research. Evidence shows that women want to see themselves as the main actor of a collaborative and interactive partnership with a competent and experienced maternity care provider who can fulfil and respect their socio-cultural, physical and emotional needs (Fontein-Kuipers et al. 2019; Leap 2009). Respectful maternity care is characterised by a due regard for the feelings, wishes or rights of others, empathy, trust and empowerment (WRA 2011). Therefore, respecting women's autonomy and involving them in the process of care with an emphasis on the physiological process would empower women and provide them with a sense of safety (Ali & Strøm 2012; Leap 2009; Small et al. 2008) and encourage them to engage in their care process (Green 2012). However, my study found such support to be largely absent in the stories that the women told of their maternity care.

A woman-centred approach should be at the core of maternity services. However, this cannot be achieved unless health providers are responsive to the specific needs of women, and respect their cultural values in a timely and professional manner (WHO 2018c). Evidence shows that such respectful care is not always provided to all women and the use of digital devices and other medical technologies rather than a direct conversation with women may create further barriers to respectful communication between maternity care providers and women (Lunda, Minnie & Benadé 2018). Women in my study call for midwives to acknowledge that they are equal partners with women in care processes and request that midwives have comprehensive cultural and clinical knowledge to make this happen. Evidence from the Netherlands shows that midwives who lacked a broad understanding of the philosophy of woman-centred care failed to integrate these principles in their daily practice and were therefore unable to develop respectful relationships with women where responsibilities were shared (Fontein-Kuipers et al. 2019). A training resource package developed in the US was designed to support health providers and communities in promoting woman-centred and respectful maternity care (Ndwiga et al. 2014). However, to make a sustainable change and improve the quality of care for women, such education needs to be developed in collaboration with all levels of leadership, management and clinical staff, as well as women (Ratcliffe et al. 2016).

Despite evidence on the benefits of a woman-centred approach, there is data that shows a lack of clear standards and indicators to measure the principles of woman-centred care in maternity services. Reliable and valid tools are needed to assess such care (Brady, Bogossian & Gibbons 2017). Defining high-quality and safe care was challenging for some women in my study, as they had not always been fully engaged in all aspects of their maternity care. The health system must offer women adequate support to enable them to be empowered to communicate, to ask for help and question their care (Barnett 2000; Higginbottom et al. 2014; Shaw et al. 2016). Health providers need to support each woman by respecting, listening, believing in her potential and offering her a care plan that meets her values and needs and enables her to gain an acceptable degree of control over her care (Berg, Asta Ólafsdóttir & Lundgren 2012).

My study advocates for strategies to empower women and ensure that effective communication and woman-centredness is embedded in all models of maternity care (Higginbottom et al. 2014; WHO 2004). Women want to feel safe and have a sense of belonging and input into decisions that affect their own care. They want to work in partnership with the health system. Policy makers and health professionals must commit to shared power and the provision of an enabling environment that places women at the centre of their care.

Empathic maternity care

In my study, women wanted health providers to feel their pain as human beings, be sensitive to their particular needs, respect their beliefs and culture, and provide care with empathy. It is important for women that their health care providers spend adequate time with them to understand how stigma, trauma and vulnerability affected their health. They also wanted maternity care providers to be informed about effective ways to support them by identifying women's particular needs and preferences, as highlighted in other research (Iravani et al. 2015). Women want to be cared for by providers to whom they can relate their personal experiences, and who are caring, kind and compassionate. In my study, women expressed the need to feel they are heard and understood, which is similar to other studies (Glasper 2012; Origlia et al. 2017). Where women felt that their freedom of choice was denied, their voices not heard or their values dis-respected, they were uncomfortable and unwilling to share their issues or disclose their problems.

The WHO (2018a) recognises empathy and listening as primary skills that are required by a provider caring for women who have undergone FGM. Empathy is defined as ‘the ability to identify or understand the perspective, experiences or motivations of another person and to comprehend and share another person’s emotional state’ (WHO 2018a). The characteristics of an empathic relationship in health care include allocating familiar service professionals who provide compassionate and attentive care that engages women (Lindsay et al. 2012). Women in my study expressed the need for adequate time with health providers, eye contact during consultations and empathetic responses when they shared emotional stories of their traumatic experiences. Evidence has shown empathy improves the quality of health care by enhancing the women-provider relationship, motivating women to liaise with their care providers and improving diagnostic accuracy and health outcomes (Lelorain et al. 2012; Lindsay et al. 2012; Mercer & Reynolds 2002). It has been argued that modern health care not only involves technological knowledge and clinical evidence but includes other aspects of care, such as compassion and kindness (Cole-King & Gilbert 2011). Women in my study acknowledged that establishing an emotional connection and attention to their feelings would improve their satisfaction. Evidence shows that a supportive work environment and health professionals’ awareness of service users’ cultural information are the pre-requisite and primary enablers in the provision of empathic care (Christiansen et al. 2015; Jakimowicz, Perry & Lewis 2018). Other studies have shown that the attitude of service providers is critical for developing empathic care and they need to understand the needs of women with the goal of helping them, rather than judging them (Lindsay et al. 2012). Women in my study noted that maternity care providers not only need to be trained in cultural and contextual diversity but also be aware of their own interpersonal skills and have empathy with women. The empathic approach is fundamental for delivering holistic and high-quality care for women affected by FGM. Involving women in the process of their care and having them participate in the co-design of services is likely to improve an understanding of women's experiences bringing recognition of the often unpredictable challenges and difficulties women face in their encounters with health services.

Co-designing education and training for health care professionals

Women in my study described the need to improve their own knowledge of health issues as well as the FGM-specific knowledge and skills of health professionals. Women spoke about their desire for normal birth and were concerned that health professionals, who had little experience of caring for women with FGM, may categorise them as high risk. Some women believed that the low level of cultural and FGM-related clinical knowledge of health providers may lead to inappropriate decisions, interventions or referrals, which could be potentially distressing. Midwives have a key role to play as advocates for normal birth. However, without FGM-specific knowledge, it is challenging for them to fulfil this and establish collaborative relationships with women (Svensson, Carlzén & Agardh 2017). Participants in my study stated that if women were able to contribute to the design and delivery of their maternity care, these services would be better able to offer culturally safe and responsive care. Evidence also shows that despite challenges to achieving such collaborative processes women can be meaningfully engaged as equal contributors.

Patient participation in the process of service design and delivery is often missing, as patients may be perceived to have inadequate medical and clinical knowledge (Longtin et al. 2010). However, service users can contribute expert knowledge about their own situation that can meaningfully contribute to the understanding of service delivery (Henderson 2003). Consumers in the US have been involved as members of obstetric technical or advisory committees where they provide input into the development of clinical protocols and standards of practice to improve clinical safety (Pettker et al. 2011). A review of the literature found that service user involvement in training health providers ensures that the health system reflects their needs and desires in the design and delivery of services (Repper & Breeze 2007). There are also examples of successful consumer partnerships where consumers have contributed their experiences to developing learning materials in nursing curricula (Ingham 2001; Sawley 2002). These kinds of collaborative partnerships have been found to have a positive impact on nursing practice by improving communication and shared decision-making (Kieft et al. 2014). Another example from the field of mental health demonstrates the benefits of sharing the experiences and insights of patients through story-telling and using different aspects of personal experience in the development of a mental health assessment tool (Coupland 2001). In the field of maternal health, there is limited evidence and further research is needed to determine the best approach to engage women and evaluate the impact of their involvement in the co-design of education and training material, guidelines and health service processes.

The next sections discuss two areas that women in my study identified as central to their care. They are culturally safe maternity services and being treated as normal.

Cultural safety

Cultural safety is defined as:

> '[A]n environment that is safe for people: where there is no assault, challenge or denial of their identity, of who they are and what they need. It is about shared respect, shared

> meaning, shared knowledge, and experience of learning, living and working together with dignity and truly listening’ (Kruske 2012).

Women in my study described the need for health providers to receive special training on the cultural aspects of care for women from diverse backgrounds. This would help to address their need for a model of maternity care that integrates a woman’s cultural and individual values with excellent communication and referral paths to promote her well-being and safety, as described in other research (Beckett et al. 2014).

Women in my study emphasised the importance of respectful maternity services that seek to engage women as partners and recognise cultural diversity. Such an approach will ensure equitable access to all services. Studies have shown that the full implementation of cultural safety including services that respect diversity and provide culturally appropriate communication in clinical practice is challenging (Ebert et al. 2014; Love & Norton 2015). This requires maternity care providers to be culturally aware and educated in an enabling environment with adequate support at policy and practice level (Ebert et al. 2014; Love & Norton 2015). However, women in my study reported that some health providers were unprepared and less likely to be aware of such minority women’s socio-cultural and emotional needs and be less able to refer them to appropriate psychological or support services. Other studies have noted examples where health professionals were unprepared to care for women, such as cases where health care providers were visibly shocked to see a women’s infibulated vulva for the first time during labour (Berggren, Bergstrom & Edberg 2006; Dawson, Turkmani, Fray, et al. 2015; Thierfelder, Tanner & Bodiang 2005). Some women in my study felt that health professionals had not provided them with important information about services. Women said they were reluctant to disclose their FGM-related issues with health providers that, as shown in other studies, made effective communication and culturally appropriate care more challenging (Berggren, Bergstrom & Edberg 2006; Hach 2012; Moxey & Jones 2016).

In culturally diverse countries such as Australia, it is crucial that maternity services recognise the difference and strive to provide culturally appropriate care (Kruske 2012). Despite the promotion of holistic care as the core of maternity services in Australia, women from migrant or refugee backgrounds often face challenges accessing culturally safe health care which can further disadvantage them (Hach 2012). Women affected by FGM require a holistic approach to maternity care that takes into consideration their culture, language and involvement. Health professionals need to understand the balance in power relations and negotiate the care plan with service users, to determine the level of control they have over their care and how their desires are met (Richardson 2011). Women in my study reported that health professionals need to expand their understanding of culturally sensitive issues through the use of appropriate language, and with consideration of families or partners in decision-making.

My research suggests that the implementation of culturally safe care is not only the responsibility of the health system but also of women themselves. Women must understand their own needs and build a partnership with health care providers to shape their care experiences in a positive way Women, as care recipients, need to define their physical, psychological and emotional needs and recognise their social, spiritual and cultural beliefs (International Confederation of Midwives 2014). As a result, women are more likely to get a sense of belonging, feel empowered and connected to a health system that is culturally safe and tailored to their needs (Ebert et al. 2014; Kruske 2012).

Many women in my study felt disempowered and trapped between two cultures. This is described by other research that identifies women’s experiences of moving from a culture of shame for not being cut, to another culture of shame and stigma for being cut (Love & Norton 2015). This situation can increase a woman's vulnerability and placed them in a position where they relive their trauma and as a result are exposed to more harm (Love & Norton 2015; Vloeberghs et al. 2012). Incorporating women's views and experiences into clinical practices and the design of services may re-shape their beliefs and increase their trust in the health system (Jorm et al. 2009).

The involvement of consumers in teaching health professionals may be a useful strategy to increase the knowledge of clinicians. One study that investigated the outcomes of learning where consumers delivered classes, found that nursing students improved their cultural knowledge and understanding of empathic care (Stickley et al. 2009). The involvement of mental health consumers in the education of nurses also showed improvements in nurses' communication skills and decreased cultural barriers for consumers as well as reduced discrimination (Simpson et al. 2008). Evidence showed that integration of cultural safety in practice is challenging as it requires the involvement of service users in the co-design of such services, and in involving a vulnerable population requires a paradigm shift in power differences between service users and health professionals (Ebert et al. 2014; Minogue et al. 2009; Rhodes 2012).

Being treated as normal

Some women in my study reported having had caesarean sections and other forms of obstetric interventions. Most women believed birth to be a normal biological and empowering process and thus did not feel that there was any need for medical interventions. The availability of the emergency facilities and professionals who have the required skills to deal with unforeseen complications made women in my study feel safer but did not discourage them from having a normal birth. Although women acknowledged the necessity of medical interventions in exceptional circumstances, they wanted to be fully informed about all the available options and be reassured of the outcome and the safety of any intervention provided by health providers. These issues have also been identified by WHO (2018c).

Most women in my study believed that they are often categorised as high-risk due to their FGM regardless of the presence of other risk factors. In HIC contexts, FGM has often considered a risk factor and can increase the likelihood of interventions (Berg et al. 2018; Varol et al. 2016). This is largely due to the lack of experience many health providers have caring for women with FGM.

Many women in my study felt that giving birth in a modern and highly advanced Western setting was a positive experience. Women described feeling reassured as they had access to such health facilities, but not all women felt safe with health professionals who were not seen as being culturally competent. Women's narratives from other HICs also show a lack of confidence and trust in the health system and health providers' skills (Turkmani, Homer & Dawson 2018). Lupton (Lupton 1997, pp. 100-02) argues that because Western medicine treats pregnancy and childbirth as an illness, this changes the social narrative surrounding normality of pregnancy and childbirth in a Western context. Other researchers have shown that this medicalised approach may influence a woman's choice of a normal birth, opting instead for a more intervention focused approach (Fenwick et al. 2010). As observed in my study, some women believed that a caesarean section is a safer way to give birth. Evidence also shows these high-risk views toward pregnancy and childbirth are the result of a lack of confidence and trust of the Western health system's preparedness in dealing with FGM (Ameresekere et al. 2011; Murray et al. 2010).

Most women in my study who reported complications and medical interventions during their pregnancy and childbirth, thought that interventions in childbirth were part of maternity care in a Western public hospital. This concurs with other studies (Berggren, Bergstrom & Edberg 2006; Essen et al. 2000; Vangen et al. 2004) that also found that women associated giving birth in public hospitals with a lack of choice (Lundgren 2010). An unfamiliar context and culture, along with a low level of literacy and health-related information influence women's understanding of maternity interventions (Ameresekere et al. 2011; Bohren et al. 2017). A lack of contact with the health system, may also result in inadequate engagement and compliance and consequently, a higher risk of complications and interventions (Berg & Underland 2013; Murray et al. 2010). Culturally sensitive health education can be a successful approach to improving health literacy and can assist women to advocate for normal birth (Svensson, Carlzén & Agardh 2017; WHO 2018b).

A woman's expectation of a normal birth may not always be a realistic decision and sometimes her culture, beliefs, or past experiences can influence her decisions, which may not be safe (Dietrich 2010; Jullisson, Karlsson & Garling 2005). For example, in my study, women compared their current childbirth experiences with their previous experiences or the experiences of other women back home. When probed, they mostly linked undergoing normal birth to cultural and faith issues. For instance, women used phrases like 'this is our belief', 'our culture consider us as weak' or 'God can manage it if he gave us the baby'. A health professional who recognises these issues and is aware of women's perspectives and beliefs can initiate meaningful communication with women using her clinical and cultural knowledge (Cipolletta 2012). In such a situation, a culturally competent and knowledgeable provider needs to have a structured conversation with women and together make a decision that is safe and informed. However, while women need to have a choice, they also need to have a clear understanding of their medical condition. Hence, a collaborative approach to decision-making can help to achieve a better outcome for a mother and her baby.

Summary

There is an emergent need to design health literacy resources for women with FGM and their families. Health information and resources that fulfil the needs of women affected by FGM must have their direct input.

My study highlighted the gaps in the provision of culturally safe maternity services for women affected by FGM. Women should be involved as co-designers in the design of services. Both men and women need to have an open discussion about the cultural practice of FGM. Therefore, involving and educating men through community-based programs is also crucial to bring positive change within the community and to abandon FGM practice.

Women and their families need to be better informed about the services available to them and midwives have a significant role in supporting women to access appropriate health services. Additionally, where there is a need for the development of new support services, women's experiences and understanding should be acknowledged.

Strengths

My study had several strengths. It is one of first of its kind to analyse this group of women's views and experiences of their own maternity care in Australia. The voice of women provides useful knowledge and may have a significant impact on improving the quality of maternity care for marginalised women.

Including women's perspectives was a unique way to explore the women's experiences and based on that, to evaluate the quality of maternity care in Australia. This means that the study can shed light on women's experiences of maternity care. It can also provide useful information to the Australian health system and policymakers for future modification of healthcare policies and plans to improve the quality of maternal care.

I was assisted in this process by including a member of the community in the research and this improved building a trust-based relationship with a group of women who have experienced socio-cultural trauma, as documented by other evidence (Tse et al. 2015). Using this approach, I was able to reach diverse ethnic minority women from different countries and religious backgrounds who are often hard to reach. Therefore, this study adds to knowledge of how to engage women and their communities in order to develop future health interventions, bring improvements and create change.

Use of AI as a methodology was unique and successful, with women focused on their positive experiences and coming up with innovative ideas or solutions for future action and changes within the health system (Mohr & Watkins 2002). By focusing on the past experiences and values, women were able to discuss new opportunities and hope for future change and embrace it.

Limitations

This study was conducted in one Australian state (NSW) and only women who lived in Sydney were included. NSW is a multicultural state and generally well-resourced in terms of services available to the migrant population. Therefore, the results may not be generalisable to the other states across Australia and suggested solutions and recommendations might be specific to the local context.

The distrbution of different ethnic groups across states is different, with Melbourne and Sydney having the highest concentration of migrants and refugees (ABS 2019). It is possible that women from a different ethnic group who might be affected by FGM practice, may have had more negative or more positive experiences compared to other women, but this cannot be established through my study findings. There is a need to conduct national research with larger numbers of women to allow for more comparative analysis between states.

Sampling bias is a possible limitation, although this was a qualitative study that was aiming to be broadly representative. With restricted selection criteria, potential women with different characteristics may have been excluded. I recruited potential women through chain referral sampling. Therefore, those who decided to participate in this study might have had more interest in this subject area and this might have led the discussion either more positively or negatively.

Recruiting women with reasonable English skills may have led to selection bias. Most women were from a refugee and migrant background and some of them had limited English proficiency. Some potential women may have been excluded due to language barriers. Therefore, the findings may have been different, if we conducted the research in women's own languages.

The recall period in this study was limited to the past 10 years since women had last given birth. It could be argued that this was too long but as evidence suggests we minimised the recall bias by asking clear questions through a collaborative approach which enables women to recall their experiences vividly (Bradburn, Rips & Shevell 1987).

The interpretation of data was complex due to the presence of cultural factors (Chin, 2005, p. 111) during discussions and interviews. For instance, the conversation was sometimes influenced by cultural complexity, which I as a researcher might not be aware of or was not able to identify. Therefore, I was purely dependent on the content of conversations to get the essence of women’s experiences.

I was aware of the fact that I needed to keep my research completely objective and not take advantage of my position as an insider and as a researcher in the area (Blythe et al. 2013; Moore 2012). Nevertheless, my background and my involvement with the topic prior to my PhD and my personal interests and values might have influenced the objectivity of the interpretation of the findings. In addition, I believe my position as a woman and as someone who has come from a similar context and culture may have influenced my interaction with women and influenced their engagement to articulate their experiences. The other limitation was that I did not use AI as a methodology in my experiences prior to this study and I learned AI through the process of this project.

Implications and future research

The findings of this study will interest not only researchers who study women’s health and quality of care, but also health care authorities, donors, communities and other stakeholders who seek to improve access to quality maternal health care in HICs for women with FGM. My study built on previous research in the area of improving quality maternity care with a focus on women personally affected by FGM who had migrated to a HIC (Njue et al. 2019; Turkmani, Homer & Dawson 2018). My study provides an additional and more in-depth understanding of the complexities of providing holistic, individualised and culturally safe services within health care settings for women with FGM. While my study has uncovered many unique issues, it has also left many unanswered questions.

The study identified barriers to trauma-led care, to address mental health concerns and the emotional well-being of these women. This has not been realised before and needs further investigation. As a strategy, women suggested establishing community-based innovative interventions, for instance, a women-led support network where women can share their experiences and provide emotional support to each other without being judged or stigmatised. However, further work is needed, as there are limited evidence and information available in the area of FGM and mental health support in HICs.

While the Australian health system aims to provide universal access to health information and culturally safe services, my study found there is a gap in health literacy among these women. This could be due to language barriers and the functionality of health literacy programs for this group of women and inefficiency of communication. My study has uncovered important cultural issues that could be incorporated into the design of health literacy resources in the future, in order to address the needs of this group of women during maternity services, for example, women could co-design training material and act as co-trainers for health providers' cultural education (Caplan & Cordero 2015; Wills 2009). My work has also highlighted that communities and women need to take part in the design of resources and programs concerning their health.

My research demonstrates that this group of women are willing to be engaged and be part of a collaborative approach to improve the quality of health care. Future health services for these women need to be co-produced with their involvement. Future investigation is needed to evaluate existing approaches and navigate future strategies to create a supportive and enabling environment for women and communities. Although, this study recommends women's contribution to service design, the practicality and levels of such involvement within the health sector will need to be carefully investigated.

My study suggests that educating and involving men in an open discussion with women through community-based programs is pivotal to bringing positive change within communities. However, further research is needed to explore and evaluate the implementation of such interventions and their impact on women's health.

My study was not engaged with healthcare providers and so there has been limited opportunity to communicate the findings. Therefore, future work is needed to explore how we can build a link between health providers' knowledge and community experiences in order to develop culturally safe services that could fulfil needs of these women and support health providers in dealing with culturally complex issues, such as FGM.

Conclusion: Women as equal allies in the design of their own health care

This is the first study of its kind in Australia to add a deeper understanding concerning the determinants of high-quality maternity care based on women's experiences as service users. The research reveals that women with FGM have a strong desire to be part of their maternity service design and evaluation. However, my study also identified the inadequacy of women's health literacy and how this prevented women from being involved in making decisions about their own care.

Women have a unique understanding of issues surrounding their health and culture and may have innovative ideas to improve health outcomes. Therefore, it is essential that all interventions that promote the wellbeing of women directly involve and engage them as equal allies and contributors in the design of health care services. By centring women and collaborating with them to identify their needs, high-quality health services can be designed in a way to ensure and sustain equality and equity of care for women affected by FGM.

The co-production of maternity services and positive changes in service users' experiences may involve a paradigm shift from a top down to a more bottom up approach.

This change will take time, as it will require policy reform and change in practices. For such a systemic change to take place women must be adequately empowered to become involved in working together with maternity care providers in an enabling health system environment supported by appropriate policies and guidelines.

Any future maternity health strategies, intervention and resources specifically targeting women with FGM are likely to be more effective if they are co-produced with women and involve their partners and communities. FGM is a complex health and socio-cultural issue and involving service users in improving the quality of care is challenging, but necessary. Health care providers and women might see the same problem within health services differently, or health providers might not identify the gaps unless women's knowledge, experiences and views are shared in a safe and common space.

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Appendixes

Appendix 1: Field Guideline

Date and time:

Study ID:

Country of origin:

Years live in Australia:

Age:

Age Undergone FGM:

Number of Children:

Number of children born in Australia:

Date of latest birth in Australia:

Educational level (primary, secondary, higher education):

Job:

First language:

Research questions:

1. What do women affected by FGM perceive as quality maternity care?
2. How do women with FGM feel that their culture is acknowledged by maternity care services and how could this be improved from the perspective of cultural safety?
3. How do the relationships that women affected by FGM have with obstetricians, midwives and other health professionals during pregnancy and after birth impact on quality care?
4. How have women with FGM experienced maternity care decision-making and how do women think decision-making could be improved?

5. What expectations do women with FGM have of maternity health services in Australia and were they satisfied with the care they received?
6. How can women with FGM be more involved in the co-production of maternity care, services and information?

Note: we will use whichever term the women feel most comfortable with.

Questions for interviews and FGDs

The questions will be broad and will essentially address the 4 D model of appreciative inquiry – Discovery, Dream, Design and Develop. The 4D words in the model will not be used in the interviews but are provided here to illustrate the process.

Discovery (Individual interview)

I am interested in your experience with health care in Australia when you were pregnant and had your baby. Can you tell me how that was for you?

Depending on what the woman says, some trigger questions or additional points may include:

a) Was there anything that made it a good experience for you and your family?

b) What was the situation in that particular context that makes you satisfied?

c) Were there any times that were less good for you?

d) Did you feel you could decide what you wanted?

e) How were the doctors and midwives who cared for you? Did they do anything especially good?

f) How ere your cultural needs taken into consideration by the staff? (What was the core factor that effect your culture during this experience of healthcare and how?)

g) What else?

Dream (Individual interview)

a) If you had a baby again what would you like to happen that was different to what happened to you?

b) If your sister or daughter was to have a baby in the future, what would you like for her?

c) What would you do for women like yourself if you were a health provider in Australia?

Design (FGDs-Workshop)

a) What do you think needs to happen for your dream to be a reality?

b) What three wishes would you make to improve maternity for women affected by FGM?)

c) What is the most important thing that contributed to y our health during maternity care?

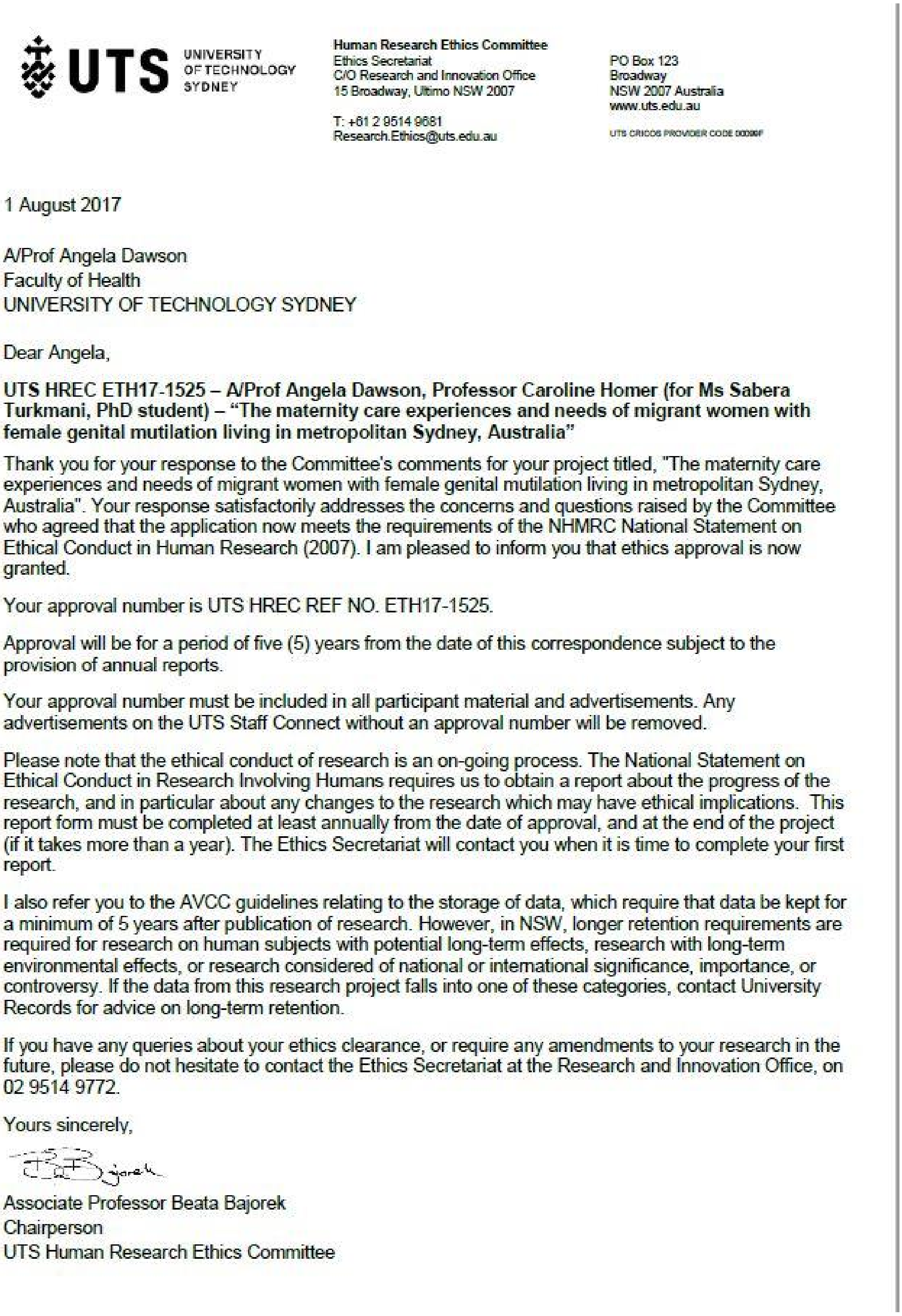
d) How can health services offer assistance in ways that women with FGM are most likely to accept help and benefit from it?

Develop (FGDs-Workshop)

a) What can we do together to contribute to your dream?

b) In what way would you are your family or community like to be involved?

Appendix2: Ethics Approval Letter



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1 August 2017

A/Prof Angela Dawson
Faculty of Health
UNIVERSITY OF TECHNOLOGY SYDNEY

Dear Angela,

UTS HREC ETH17-1525 – A/Prof Angela Dawson, Professor Caroline Homer (for Ms Sabera Turkmani, PhD student) – "The maternity care experiences and needs of migrant women with female genital mutilation living in metropolitan Sydney, Australia"

Thank you for your response to the Committee's comments for your project titled, "The maternity care experiences and needs of migrant women with female genital mutilation living in metropolitan Sydney, Australia". Your response satisfactorily addresses the concerns and questions raised by the Committee who agreed that the application now meets the requirements of the NHMRC National Statement on Ethical Conduct in Human Research (2007). I am pleased to inform you that ethics approval is now granted.

Your approval number is UTS HREC REF NO. ETH17-1525.

Approval will be for a period of five (5) years from the date of this correspondence subject to the provision of annual reports.

Your approval number must be included in all participant material and advertisements. Any advertisements on the UTS Staff Connect without an approval number will be removed.

Please note that the ethical conduct of research is an on-going process. The National Statement on Ethical Conduct in Research Involving Humans requires us to obtain a report about the progress of the research, and in particular about any changes to the research which may have ethical implications. This report form must be completed at least annually from the date of approval, and at the end of the project (if it takes more than a year). The Ethics Secretariat will contact you when it is time to complete your first report.

I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

If you have any queries about your ethics clearance, or require any amendments to your research in the future, please do not hesitate to contact the Ethics Secretariat at the Research and Innovation Office, on 02 9514 9772.

Yours sincerely,

Associate Professor Beata Bajorek
Chairperson
UTS Human Research Ethics Committee

Appendix3: Information Sheet

PARTICIPANT INFORMATION SHEET

The maternity care experiences and needs of migrant women affected with ‘female cutting/circumcision’ living in metropolitan Sydney, Australia

(UTS APPROVAL NUMBER: HREC ETH 17- 1525**)**

WHO IS DOING THE RESEARCH?

This study is being undertaken by A/Professor Angela Dawson, Professor Caroline Homer and Sabera Turkmani, a PhD student from the Faculty of Health at the University of Technology Sydney (UTS).

No FGM Australia organisation will also support this study. No FGM is a not-for-profit organisation which aims to protect Australian girls from female cutting/circumcision and to support and empower survivors of Female cutting/circumcision. This organisation will be involved in the advisory committee, connecting the researcher to the community members, facilitating the recruitment of the study population and organising the venue for interviews and group discussions.

WHAT IS THIS RESEARCH ABOUT?

The purpose of this research is to explore the maternity care experience and needs of women with female cutting/circumcision who have migrated to Australia and identify ways to improve maternity care. A better understanding of the experiences of women will help identify improvements for the future. We hope that this may help women in many other parts of Australia as well.

You have been invited to participate in this study because the voices and views of women with female cutting/circumcision as part of the health service delivery are often missing and sometime their needs and concerns about their health care not fulfilled. Your participation and involvement will engage you in a process that is aimed to improve future services for women.

WHY HAVE I BEEN ASKED?

We have asked you to participate as you have been identified as a woman who has probably had the experiences we are interested in such as you are affected by ‘female cutting/circumcision’, your age is between 18-45, had a baby in Australia, speak English and live in Sydney and you have used the maternity care services in Australia.

You will be invited to be part of a one to one interview with a female researcher. You may also be invited to be in a small group discussion with other women to help identify improvements for the future. These activities will take approximately 45-60 minutes each. Your contact detail will be obtained by the researcher in coordination with No FGM.

IF I SAY YES, WHAT WILL IT INVOLVE?

After initial consent, the researcher will then be able to make a follow up plan and meet with you to discuss further and proceed with the interview and group discussion.

The interviews will be conducted in a place which is convenient for you for eg. home. Private rooms in a library, community centre or park based on your preference. Group discussions will take place in a community centre or libraries which is convenient to the majority of the women.

In the interviews and focus discussion we will be interested in your stories and experiences. There will be no right or wrong answers. All information will be kept private and the hospitals you received care form will not have access to your information.

During the process of the interview and group discussion a member of the community will help the researcher to ensure cultural appropriateness and proper communication.

The information gathered from this research will be collated and published in a way that will not identify you. Participation in the study is voluntary. You are not obliged to participate, and you can withdraw from the study or refuse to answer specific questions at any time.

ARE THERE ANY RISKS/INCONVENIENCE?

It is possible that you might feel uncomfortable answering some of the questions if they are about sensitive topics for you, your family or your country. You are able to choose not to answer these questions or stop the interview. We will follow-up later to ensure you are well and check if you want to resume the interviewer on another day.

In case of stress we would refer you to a general practitioner (family doctor) or other organisations such as STARTTS who can provide free counselling and support. (Medicare will cover 10 sessions of counselling per annual)

DO I HAVE TO SAY YES?

You don’t have to say yes to participate in this study.

WHAT WILL HAPPEN IF I SAY NO?

There are no ramifications if you say no. We will thank you for your time so far and won’t contact you about this research again. However, *you should be aware that data collected up to the time you withdraw will form part of the research project results and* *your personal information already collected will be retained to ensure that the results of the research project can be measured properly and to comply with law.*

If you wish to withdraw from the study, you can do so at any time without having to give a reason, by contacting:

Angela Dawson, A/Professor Public Health, Faculty of Health | University of Technology, Sydney.

Phone: +61 2 9514 4835

Mobile: [redacted]

Email: angela.dawson@uts.edu.au

Or

Sabera Turkmani, PhD student, Faculty of Health | University of Technology, Sydney

Phone +61 2 9514 4852

Mobile: +61 [redacted]

CONFIDENTIALITY

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. All this information will be treated confidentially and will be kept in a locked cabinet. No names or other identifying information will be recorded. Only the researcher and her supervision team will have access to the information. Audio recording data will be stored in a secure laptop with a password which only known and accessible to the researcher. It will be shut down automatically when not in use and locked in a secure cupboard.

Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

All identifying information will be removed or rephrased (e.g. details will be changed if they had a particularly unique experience that someone might recognise). Residential details will be removed. Only pseudonyms will be appeared in the transcripts and published data. This will eliminate the chance of the participants being identified by published data.

WHAT IF I HAVE CONCERNS OR A COMPLAINT?

If you have concerns or questions about the research please contact:

Angela Dawson, A/Professor Public Health, Faculty of Health | University of Technology, Sydney.

Phone: +61 2 9514 4835

Mobile: [redacted]

Email: angela.dawson@uts.edu.au

Or

Sabera Turkmani, PhD student, Faculty of Health | University of Technology, Sydney

Phone +61 2 9514 4852

Mobile: +61 [redacted]

Paula Ferrari

Managing Director, No FGM Australia

T: [redacted]

Khadija Gbla

Executive Director, No FGM Australia

Tel: [redacted]

If you would like to talk to someone who is not connected with the research, you may contact the Research Ethics Officer on 02 9514 9772, and quote this number "?????" *(UTS HREC Approval Number)*

NOTE:

This study has been approved by the University of Technology Sydney Human Research Ethics Committee [UTS HREC]. If you have any concerns or complaints about any aspect of the conduct of this research, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au], and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

Appendix 4: Consent Form

CONSENT FORM

The maternity care experiences and needs of migrant women affected with 'female cutting/circumcision 'living in metropolitan Sydney, Australia

UTS HREC APPROVAL NUMBER

I ____________________ agree to participate in the research project on '*The maternity care experiences and needs of migrant women with female genital mutilation living in metropolitan Sydney, Australia'*

UTS HREC approval reference number when obtained] being conducted by Sabera Turkmani, PhD student at University of Technology, Sydney, Faculty of Health, Ultimo NSW 2007, Tel: 02 9514 4852.

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research as described in the Participant Information Sheet.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time without affecting my relationship with the researchers or the University of Technology Sydney.

I understand that I will be given a signed copy of this document to keep.

I agree to participate in:

☐ Individual interviews

☐ Group discussions

☐ Both

I agree to be:

☐ Audio recorded

I agree that the research data gathered from this project may be published in a form that:

☐ Does not identify me in any way

I am aware that I can contact *Angela Dawson, Principal Investigator and Sabera Turkmani, PhD candidate* if I have any concerns about the research.

Contact details:

Angela Dawson

Phone: +61 2 9514 4835

Mobile: [redacted]

Email: angela.dawson@uts.edu.au

Sabera Turkmani,

Phone +61 2 9514 4852

Mobile: +61 [redacted]

Email: [redacted]@student.uts.edu.au

____	____/____/____
Name and Signature [participant]	Date
____	____/____/____
Name and Signature [researcher or delegate]	Date

NOTE:

This study has been approved by the University of Technology Sydney Human Research Ethics Committee [UTS HREC]. If you have any concerns or complaints about any aspect of the conduct of this research, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au, and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

Appendix 5: Distress Protocol

The maternity care experiences and needs of migrant women with female genital mutilation living in metropolitan Sydney, Australia

Distress and safety Protocol: Woman

The following protocol will be put in place should a participant became distressed and required either additional or on-going assistance. A range of services could be offered depending on her circumstances.

Prior to the commencement of any interview, information regarding the counselling available should it be required will be provided to all prospective and actual study participants. The researcher will provide sufficient information regarding the risks and benefits of the research so that individuals may freely accept or decline participation. This information will be made available to the participant prior to the interview commencing. An additional notification of this information will also be given to those participants should they become distressed during the actual study.

Strategies to assist those distressed during an interview.

Should a participant become uncomfortable or distressed while discussing any topic during the interview, the following actions will be taken by the interviewer:

1. The researcher will suggest that it is appropriate that the interview be terminated.

2. If the participant wishes this to happen, the interview will be ceased.

3. In the case where a counsellor or GP is not readily accessible a members of the research team who is a health professional will spent time with the participant and provide assistance, within the scope of their abilities, to discuss their concerns and support them.)'

4. After seeking advice form the Chief investigator (principal supervisor), a recommendation will be made that the participant speak to a counselling professional to discuss their concerns, and referred if they agree.

- Counsellors/ psychologists will be available at STARTTS (NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors) organization as indicated in the application

- If the women has a general practitioner (GP) involved in her care it may be more appropriate to refer her to her GP who is already familiar with their history and would provide continuity of care. In this case the options of a counsellor or extant clinician would be provided to the women as well. (Medicare will cover 10 sessions of counselling per annual)

5. The intended outcome of the activation of this protocol will be a comprehensive assessment and the presentation of options regarding ongoing counselling or other management as appropriate.

6. A follow-up phone call will be made by the interviewer the following day to ensure that the participant is well and to determine the feasibility of a follow up interview if one is planned.

Distress and safety Protocol: Researcher (PhD student)

The following protocol will be put in place should a researcher become distressed or be at risk during field work and require emergency, additional or on going assistance. A range of services could be offered depending on her circumstances.

Strategies to assist those distressed during an interview.

1. The researcher have regular meeting with her supervisors

2. The researcher will be referred to a counselling professional to discuss their concerns or a referral made to their Employee Assistance Program

3. The researcher will always carry a mobile phone while working in the field and will share the contact details and location of the interviews with the research team'

Conclusion

It is the researcher's duty of care to ensure that there is a balance consideration of the benefits against the risks. She will these strategies are put in place prior to commencing the interviews or discussions.

Below are the step by step guided protocol adapted from Draucker C B, Martsolf D S and Poole C (2009) Developing Distress Protocols for research on Sensitive Topics. *Archives of Psychiatric Nursing* 23 (5) pp 343-350)

Distress

- A participant indicates they are experiencing a high level of stress or emotional distress OR
- Exhibit behaviours suggestive that the discussion/interview is too stressful such as uncontrolled crying, shaking etc

Strategy1

- Stop the discussion/interview.
- One of the researchers (who is a health professional) will offer immediate support
- Assess mental status: Tell me what thoughts you are having? Tell me what you are feeling right now? Do you feel you are able to go on about your day? Do you feel safe?

Evaluate

- If participant feels able to carry on; resume interview/discussion
- If GP or counsellor may not be readily or easily accessible
- If participant is unable to carry on Go to sterategy 2

Strategy2

- Remove participant from discussion and accompany to quiet area or discontinue interview
- Encourage the participant to contact their GP or mental health provider OR
- Offer, with participant consent, for a member of the research team to do so OR
- With participant consent contact a member of the health care team treating them at for further advice/support

Follow up

- Follow participant up with courtesy call (if participant consents) OR
- Encourage the participant to call either if she experiences increased distress in the hours/days following the focus group

Participants’ Safety & Distress Protocol:

Safety & Distress

- The researcher should be considered any indication of a "safe" working environment while also maintaining the "quality" of the research
- The researcher should consider the potential physical and psychological impact on the researcher of the participants description of life experiences
- The researcher should consider how many interviews could be undertaken in a week to manage her distress
- The researcher should be aware of the potential for emotional exhaustion

Strategy

- All the contact details and location of the interviews will be shared with research team
- Involvment of a community member as point of contact in the research project
- If the topic is potentially sensitive/distressing data collection need to be undertaken by support of another member of the research team
- Regular scheduled debriefing sessions with supervisors
- To journal her thoughts, reflections and feelings which may then become part of fieldwork notes

Evaluate

- Is there proper chain of communication in case of emergency or risk
- Is there alerted emotional states prior, during or after data collection
- Is there any feelings of potentially "challenging" or "difficult" interviews
- Has been attending regular scheduled debriefing sessions with supervisors

Follow up

- The researcher to access to a counseling services or a research mentor if she experiences increased distress
- The researcher have all the contact numbers and communicate with a team member during and after field work

Researcher's Safety and Distress Protocol:

Appendix 6: Sample of Initial Coding of Data

Initial coding and categorising		
Code list	**Categories**	**Initial Themes**
Ask about FGM, history, continuity of care, midwifery care, autonomy, providing information, respect, trust, Waiting, decision making, informed choice, options, cultural dilemma, feelings of confusion, feeling of lost, kindness, friendly, helpful, supportive, attentive, Australia vs home country, physical check, Trauma, class and care, self-awareness, community awareness, knowing your rights, ask questions, privacy, follow up after birth, preparedness, birth plan, assurance and safety, being heard, gaining new knowledge, bonding, touching, frustration, unclear instruction, rush, labelling, wrong vs right, push normal birth, close us after birth, a midwife who knows everything, have skill, have knowledge, female vs male provider, being among similar culture, having a midwife from my own culture, disturbance, racism reactions, record my information, repeated FGM cases, train health providers, report FGM cases, ongoing practice, pressure on families, men involvement, get words out, talk openly, next generations, reverse FGM, support services, teach about sex life, specialised care, assumptions, peer influence, complication, shame, stigma, facial expression, delay seeking help, public vs private, allocating time, caring, shocking, angry, fear, attacking, smile, kind face, clear direction, school education, link communities with government, know our rights, talk openly, training, open the conversation first, feeling of disappointments, being judged, surprised faces, disgust, treat me like others, treat me as normal, accommodating, understanding, professional, being looked down,	Responsiveness Attributes of quality care Sense of control Rarely count as a high risk birth Sense of specialness Future directions Appreciations Adjust culture Language, Communication Fit for purpose information Dynamic of interactions coping over time Collaborative decision, involvement in the planning Flash back Adequate support services Accessibility, fairness, and equality Accountability Rationality Care avoidance Competent workforce, Advocacy and support services Government/ community and gender role	**Discovery**: ✓ I did not disclose my FGM,I thought eventually they will ask me ✓ They gave me flyers and information but nothing about FGM ✓ Despite I told them I am circumcised I saw all these judgmental and surprised faces ✓ Feel lonely and different to other people ✓ I got attentions that I need to ✓ The way she was talking to me and touching me all were remarkable ✓ I was with one midwife all the time which was excellent
		Dream: ✓ I want doctors and midwives from same cultural background ✓ Reverse it if there is a way ✓ Have a room by myself ✓ Want midwives with first-hand experience ✓ Let me know everything I need to know before I lay on that bed ✓ Ensure me everything will be ok and safe ✓ Ask me what cultural support I need ✓ Want natural experience
		Design: ✓ Diversifying and increase midwives ✓ Train providers on FGM ✓ Get words out ✓ Women needs to be educated on their rights ✓ We are not the same as other women treat us differently ✓ You need to question a woman who appearing repeatedly in the hospital with FGM ✓ Bring up stories of women who are suffering ✓ Shouldn’t point at anybody’s culture or religion

		✓ Helping women to understand F and it is ok and they are not alone ✓ Give us all the options in advance ✓ Access to after birth support services ✓ Not every birth is the same ✓ Communities need to be in touch with the government ✓ Providers need to open the conversation first
		Develop: ✓ Empower and educate women ✓ Men need to talk to men ✓ Change start with each family ✓ Develop a system with volunteers to guide us through health system ✓ Doctors and midwives need to talk to families ✓ Need for an information system within community