

**ROADS OF RESTORATION AND RESILIENCE:  
A JOURNEY INTO CLITORAL RESTORATION SURGERY IN CANADA**

by

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## **Abstract**

Female genital cutting (FGC) has a profound impact on the physical, mental, and sexual health of survivors - leading to various long-term health complications overtime. Clitoral restoration surgery (CRS) has emerged as a potential solution to these complications through the surgery's acclaimed ability to alleviate pain, restore sexual function, and improve survivors' sense of self. However, these claims have been challenged, highlighting insufficient evidence and lack of consideration for the psychosexual and cultural contexts that influence survivors' surgical outcomes. Therefore, understanding FGC as an ongoing experience rather than a one-time event emphasizes the complexity of its effects on survivors. In order to account for this complexity, this study employs a combination of theoretical perspectives, including complexity theory, intersectional feminist theory, and multisystemic resilience. These frameworks help to investigate questions of Canadian survivors' motivations in electing to undergo CRS, the specific complications they must present with in order to qualify for this surgical procedure, and physicians' decision-making when it comes to identifying potential candidates. Through survivors, care providers, and FGC-related organizations, this study explores these questions.

By examining the decision-making process between physician and their patient, this study emphasizes the importance of individualized care that accounts for survivors' unique physical, social, and cultural contexts. Additionally, this research underscores the importance of more holistic treatment options, such as psychosexual therapy and sexual education, as potential alternatives to CRS. These approaches may help to address survivors' health concerns without the need for surgical intervention. By promoting awareness of these alternatives, the study encourages a more comprehensive understanding of healing that moves beyond physical health to also emphasize survivors' mental and emotional well-being along their healing journeys.

Lastly, by contributing to the limited body of knowledge on CRS and FGC-related care more broadly in Canada, this research helps to raise awareness of the challenges faced by survivors, combat stigma in health-care settings, and support the development of relevant health policies. Insights gained from survivors, care providers, and FGC-related organizations in this study highlight the interconnectedness of these groups - fostering collaborative efforts to improve survivor care and support services in both Canada and abroad.

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## Chapter 1 - Introduction

### Vignette

***February 20<sup>th</sup>, 2024***

The pale pink hospital stood out amongst a sea of sand-coloured exteriors. I hopped out of the Uber – thanking the driver.

“Shukran”, I said closing the door behind me.

As I made my way through the entrance doors I was met by two smiling clinic administrators.

***February 20<sup>th</sup>, 2023***

*The first time I heard about Restore FGM was while I was conducting fieldwork in Toronto, Ontario. During this period, I came across an Aljazeera article titled “‘Starting over’: FGM clinic gives hope to traumatised Egyptians’. However, it was not the title itself that caught my attention, but rather what came after – reconstructive surgery and multidisciplinary treatment. Restore was the first clinic in Egypt to offer FGC survivors this type of care. The type of care I was exploring in Canada.*

Now exactly one year after since I had read the article and subsequently reached out to Restore FGM, I was in Cairo ready to meet with the clinic’s founding physicians.

“As-salamu alaykum. I’m here to see Dr. Awwad”, I said.

The administrators smiled and told me it would be 400 EGP.

“Oh, I’m sorry, I’m not here for a doctor’s appointment”, I explained. “I am here for a meeting – a research meeting.”

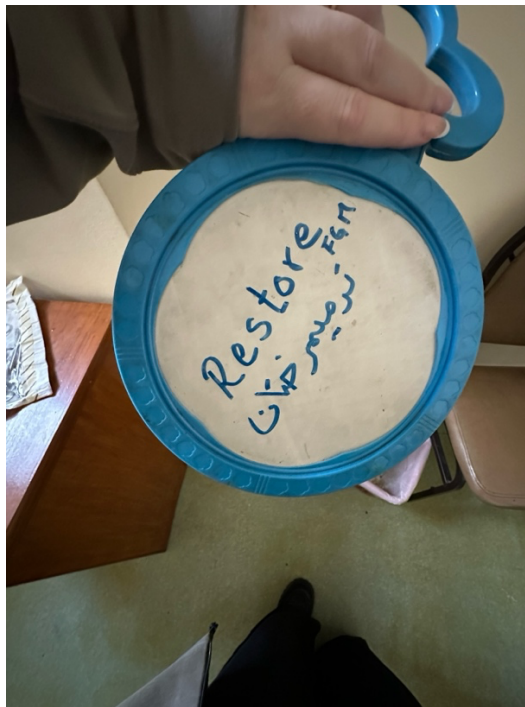
The administrators smiled again and nodded in understanding as one excused herself around the corner – letting me know she would only be a moment.

*Upon reading through the article, I was quick to reach out to Dr. Awwad to learn more about the types of services she and her colleagues' offered survivors. Three days after our initial email exchange, I met with Dr. Awwad and her collaborator Dr. Seifeldin over Zoom. While I sat at the dining table in my Toronto apartment rental, Dr. Awwad, Dr. Seifeldin, and myself connected over their work on clitoral restoration, their clinic operations, and their emphasis on non-surgical treatment options for survivors. After this initial meeting, Dr. Awwad and I kept in touch – emailing ever so often over the next few months.*

When I came around the corner, I was greeted by Dr. Awwad in her office. Despite this being our first time meeting each other in-person, after months of talking it felt like reconnecting with an old friend. In addition to Dr. Awwad, we were briefly joined by Dr. Seifeldin and a visiting medical student from America. The Restore team had just arrived back in Egypt from Geneva, Switzerland where they had attended their first ever masterclass in surgical interventions for FGC survivors where Dr. Seifeldin was invited to moderate. It was an event that brought together experts in the field of FGC-related care and relevant procedures from all corners of the globe – including Canada. We spent the next few hours chatting, Dr. Awwad sharing about their time in Geneva and plans for upcoming publications and I about my research and past few days in Egypt.

I asked for a tour of their clinic and Dr. Awwad brought me to a patient room. The room was comprised of a surgical bed, chairs, desks, and a small wooden table that housed some of their consultation equipment. Alongside a box of medical gloves, Q-tips, and bottle of hand sanitizer was a handheld mirror. Circled in sky blue-coloured plastic, the handheld mirror had Restore FGM written in black marker on the back in both English and Arabic.

This is the mirror that Dr. Awwad would use in her consultations with patients. As noted in their Aljazeera article, as well as in our own conversations, Dr. Awwad had expressed how the mirror gave survivors the opportunity to familiarize themselves with their bodies in ways that most have never before. Here, with the guidance of a physician, the mirror functioned as a tool of exploration – offering survivors a chance to survey their body, their genitalia, and most importantly their **clitoris**.



*Figure 1. Restore FGM's clinic consultation mirror.*

## **Preamble**

### ***The Clitoris***

The first “discovery” of the clitoris is complex, highly debated, and most notably lacking female perspectives (Charlier et al., 2019). Dating back hundreds of years, historical accounts will argue that it was Realdo Colombo, an anatomist and surgeon from Cremona, Italy who first “discovered” the clitoris in 1559 at the age of 43 (Stringer & Becker, 2020). Here Colombo

described a woman's "seat of pleasure" in his book, *Realdi Columbi Cremonensis De re anatomica libri XV* (Charlier et al., 2019, p. 47). Others, such as some linguists, would contest that the "discovery" of the clitoris was in fact much earlier due to the uncovering of "kleitoris" in the works of Rufus of Ephesus back in the first or second century CE (Pauls, 2015, p. 377). Here the linguistic origins of "kleitoris" were found in ancient Greece and, and according to Pauls (2015), were "synonymous [with] "the veiled", "myrtle berry", and "organ hidden under the skin"" (p. 377).

If the origins of the clitoris' discovery were not complex enough on their own, it's purpose and function have been even more highly contested throughout time with descriptions ranging from "passive and unimportant" to "the most critical anatomical structure for female sexual arousal and orgasm" (Pauls, 2015, p.378). Frequently compared to male sexual anatomy, Greek philosopher and polymath, Aristotle "positioned the clitoris as a body part of embarrassing insignificance" in his 300 BC comparisons. Here the perceived "underdeveloped" female sexual organ was contrasted against the "superior" male penis (Stiriz, p.251).

This concept of female inferiority, and more specifically women's genital inferiority, was furthered centuries later by Austrian neurologist Freud who, according to Stiriz, made this belief "the bedrock of his female psychology" (p. 253) when he "re-discovered" the clitoris in 1905 (Puppo, 2013, p.145). Here Freud declared clitoral stimulation and its related clitoral orgasms as "infantile" and "superficial" in contrast to vaginal stimulation and its derived orgasms, which he argued were "mature" and much more "powerful", and therefore, similar to those experienced by men by way of penile stimulation (Puppo, 2013).

The impacts of such comparisons and descriptions have contributed to beliefs of female inferiority that continue to be felt today. Unfortunately, it would not be until 2005 that we would

have our first comprehensive description of clitoral anatomy. In quoting O’Connel, Sanjeevan, and Hutson (2005, Charlier et al. (2019) stated,

It was concluded that “the entire cluster of related tissues (distal vagina, distal urethra, and clitoris including the bulbs, ceuta, body, and glans) should be included in the term clitoris”. This cluster appears to be the locus of female sexual function and orgasm (p.48).

Finally, the clitoris was being acknowledge not for what it was not, but rather for what *is* – “the most critical anatomical structure for female sexual arousal and orgasm” (Pauls, 2015, p.378) – housing 10,000 nerve fibers, which is a 20% increase from pre-2023 estimates (Uloko et al., 2023). Such findings contributed to significant advancements in medical knowledge that have helped to strengthen our understanding of the clitoris as we have come to know it today.

Despite countless attempts to demonize, underestimate, or presume unimportant, the clitoris prevailed – unbothered by history’s one-sided mission of comparison and devaluation. Such a journey across centuries reveals a symbolic sense of resilience despite centuries of historical, medical, and social neglect and misunderstanding (Pieters et al., 2023). Ultimately, what this brief introduction into the clitoris, and its complex journey of demystification, seeks to highlight is that these beliefs are not isolated to any one place or particular group of people but rather have existed for centuries in all parts of the world. What is revealed is that these negative perceptions and inaccurate representations of the clitoris have contributed to ideas and practices across time and space which have greatly impacted this foundational component of female sexual anatomy in addition to beliefs around women and women’s sexuality more broadly.

## Statement of the Problem

### *Clitoral Restoration Surgery*

One of the most impactful practices on female sexual anatomy is the practice of female genital cutting (FGC). Many survivors of female genital cutting (FGC) will experience negative and life-long health complications associated with the cutting. These negative health complications can often be a combination of both physical and mental. To help alleviate these complications, clitoral restoration surgery (CRS) has emerged as a reparative option for survivors with the potential to help diminish pain, restore clitoral orgasm, and improve body image. In a study which offers a comprehensive review of the clitoris and its role in female sexual function, Mazloomdoost and Pauls (2015) argue, “despite these purported anatomical impacts [of female genital cutting], clitoral innervation appears resilient” (p. 259) – it is this resilience of clitoral innervation that makes CRS possible.

As a rising field of surgical work in Canada, this surgery has garnered attention by Canadian survivors across several provinces. Much of this attention stems from several surgeons’ claims that the procedure can enable survivors to become clitorally orgasmic, enhance sexual satisfaction, and help address issues related to sense of self and poor body image due to survivor beliefs that their anatomy differs from biomedical definitions of “normal” (Foldès et al., 2012; Karim et al., 2022). However, these statements have been contested by studies that argue that there is not enough evidence to support these claims (Abdulcadir et al., 2015; Sigurjonsson & Jordal, 2018; Mohamed et al., 2020; Auricchio et al., 2021). For instance, Abdulcadir et al. (2015) cite the noteworthy psychosexual and cultural implications that can impact a survivor’s surgical outcome and raise caution against interventions that fail to account for these other dimensions of one’s overall health. Similarly, in a study on rethinking female genital cutting,

principal author Käkälä (2020) encourages readers to, “conceptualize FGC as a process rather than a one-off event, as women’s experience of FGC is continuously shaped in response to their surroundings” (p.97). This understanding of FGC and its related impacts as a process offers a more in-depth understanding of the associated complexity when it comes to FGC as multilayered.

### ***Research Questions***

As discussed, the FGC-related health complications that survivors will most often experience are not simply physical. Moreover, by offering a surgical “solution” that *only* repairs one aspect of a survivor’s condition it fails to account for the complexity of many survivors’ health complications. Therefore, with that understanding and the matter of global support for CRS remaining largely unclear, it becomes important to ask **what survivors in Canada truly hope to gain from undergoing CRS in Canada?** Understanding why survivors are seeking out CRS as a reparative procedure and what they are hoping to achieve by doing so helps to determine whether CRS would be the most suitable treatment option for a prospective candidate.

From this main research question, two sub-questions emerged. Firstly, with **which FGC-related complications must survivors present in order to qualify for surgical referral, and secondly upon receiving surgery, how do their postsurgical outcomes align with their initial motivations?** With the recent introduction of CRS in Canada, it is important that studies related to CRS and FGC-related care more broadly are undertaken to help improve provider knowledge in this field. By strengthening health care professionals’ knowledge base, they will be better equipped to help guide, support, and care for their patients. Additionally, studies such as this can be used to inform the development of provincial and national health care recommendations for medical policy and clinical guidelines. The healthcare needs of survivors in Canada are

multifaceted and it is precisely this multifaceted nature of CRS and other potential interventions that requires a theoretical lens varied enough to effectively analyse the inherent complexity of this procedure and related actors. By employing a multi-system resilience perspective, this study offers insights into the introduction of clitoral restoration surgery (CRS) in Canada by way of the survivors who seek out this procedure, the physicians trained in this surgical technique, and the organizations that aid in the facilitation of FGC-related supports and services which are inherently linked to CRS.

### **Summary**

This dissertation is organized into 7 chapters. Following this introductory Chapter, Chapter 2 offers a review of the important literature in order to situate the study's research questions and key concepts relevant to the understanding of CRS – particularly within the Canadian context. The practice of female genital cutting (FGC) is outlined in-depth as the precursor to CRS, thus emphasizing the social, medical, and legal implications of the practice which can impact a survivor's decision to opt for CRS as a potential reparative option. Through discussions around national and international perceptions of FGC, comparisons of CRS with other elective genital surgeries, and issues around surgical funding and accessibility, this section outlines the complexity of investigations into CRS.

This matter of complexity is then explored in more depth in Chapter 3 which outlines the study's three theoretical perspectives that account for the study's conceptual framework: intersectional feminist theory, complexity theory, and multi-system resilience. Here Chapter 3 opens with a discussion on feminist research whereby I position myself as the researcher before outlining intersectional feminist theory and how it aligns with complexity theory based upon complementary approaches to understandings of systemic oppressions. In continuation of this



discussion, the concept of resilience is situated with the context of complex systems based upon a system's adaptive capacity, which is a key component to complex systems. This chapter then concludes with a description of multisystemic resilience, which further highlights this adaptive capacity at the individual, community, and organizational level.

In line with the intersectional feminist theoretical underpinnings of this study, Chapter 4 opens with a discussion on feminist methodology. Here Chapter 4 details the guiding feminist methodology and related qualitative methods employed in order to undertake this study. Through an overview of each of the study's key demographics, a detailed journey of rapport building is shared – highlighting relevant actors, informants, and organizations and associated secondary data. Included within is an overview of the primary data collection including focus group discussions with physicians, qualitative surveys of survivors, and the gathering of secondary data during my fieldwork in Canada and Egypt. Lastly, the chapter concludes with an outline of my process of thematic analysis whereby I familiarized myself with the data I had collected, shared my coding practice, generated themes, reviewed these themes, finalized, and named these themes, and began my report to share these findings.

With the support of rich qualitative accounts from focus group participations, interwoven with qualitative survey responses from survivors, and secondary data collected through FGC-related organizations, Chapter 5 identifies the study's four major themes and corresponding sub-themes. These themes include: the politics of decision-making (anatomy, complexity, and patient choice), storyline (trauma, learning, and healing), resources (survivors, FGC organizations, and care providers), and the Canadian issue.

Following the introduction and description of the study's themes, the findings are analyzed within the context of the study's theoretical framework and situated within existing

literature. Chapter 6 highlights the complexity of an investigation into CRS and reveals the resilience of each demographic at multiple levels to adapt to the challenges they have encountered throughout the process. This chapter concludes with a description of a complex journey of discovery which critically analyzes the potential outcomes of CRS and other non-surgical treatment options, the guidance of care providers, and the role of FGC-related organizations in improving the supports, services, and healthcare landscape for survivors in Canada.

Lastly, in Chapter 7 I offer my concluding remarks. I identify some limitations as well as highlight several of the study's strengths before outlining important contributions this project makes to the field of CRS research – particularly in Canada, in addition to key contributions to FGC-related research specifically as it pertains to health. In conclusion I share a closing reflection that speaks to the many roads of restoration and resilience – reflecting back upon early “discoveries” of the clitoris and what more there is to uncover.

## **Chapter Two – Background**

The purpose of the background chapter is to help contextualize the study and corresponding research questions by providing an overview of relevant literature and addressing key themes significant to the discussion of clitoral restoration surgery (CRS) in Canada. This chapter opens with a discussion on female genital cutting (FGC) more broadly – as a gendered socio-cultural practice it is imperative that the practice is situated within appropriate contexts – doing so helps to strengthen our understanding of the factors that may influence a survivor's decision to undergo CRS. The following section explores the legal framework surrounding FGC, which is crucial in terms of differentiating FGC, a criminalized genital procedure performed for non-medical reasons, from CRS, an elective genital procedure performed for medical purposes. The legal status of FGC in Canada is a crucial context from which to understand CRS and a survivor's decision to reach out for support from health care professionals. As part of this legal discussion, FGC as a form of gender-based violence (GBV) is briefly explored. This examination offers further insights into experiences of GBV within healthcare systems and how these instances are linked to governmental support for anti-FGC initiatives, and therefore, FGC-organizational funding.

Clitoral restoration surgery (CRS), as a site of intersecting power dynamics, is then outlined explicitly with a return to a discussion about the clitoris more generally as the focal point in this study. The origins of CRS as a surgical procedure are explored along with a discussion of some of the outcomes that practitioners claim are achievable by way of surgery. Following the introduction of CRS, the surgical procedure is then explored in relation to other forms of elective genital surgeries. Comparing and contrasting CRS with other elective genital surgeries helps to differentiate the procedure. Lastly, this chapter concludes with an examination

of perceptions of what is considered “normal” biomedically versus socio-culturally and how these perceptions of normalcy can contribute to survivors’ motivations to undergo CRS.

### **Female Genital Cutting (FGC)**

According to the World Health Organization (WHO), female genital cutting should be understood as the practice of piercing, cutting, or removing of parts of a woman’s genitalia for non-medical purposes (World Health Organization, 2016). There are several different terms used to describe this practice including female genital cutting<sup>1</sup>, female genital mutilation, female or pharaonic circumcision, and infibulation. The choice of terminology varies based on the context in which practice is being described. For instance, in comparison to sociocultural descriptions or even medical studies, the use of ‘female genital mutilation’ is much more prevalent in legal discourses. The word mutilation itself is a confronting term that can often trigger a visceral response from the reader. As such, the use of the term mutilation is to position the practice in such a way that it is emphasized first and foremost as an act of violence against women and girls (Vissandjée et al., 2014).

However, in Khadija et al.’s 2009 study exploring the perspectives on FGC of Somali women living in Canada and the United States, women shared negative perceptions of the use of female genital mutilation. In their view, the use of this term was degrading, insulting, stigmatizing, and racist (Khadija et al., 2009, p.734). This terminology led the women interviewed to feel a sense of inferiority in comparison to uncut women (Khadija et al., 2009).

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<sup>1</sup> Terminology surrounding the practice of FGM/C is greatly complex and often context specific. Within community spaces, the preferred term is female genital cutting (FGC) as it accounts for the scope of cutting practices without negative connotations or judgement-laden language. However, within legal and human rights contexts, the term female genital mutilation (FGM) is most commonly used as it emphasizes the harmful effects associated with cutting and is thus more in line with efforts to discontinue to the practice (Vissandjée et al., 2014). Ultimately, with the expansion of FGM/C research and a growing pool of literature, what becomes clear is that preferences in FGM/C terminology are continuously evolving and through that process my own terminology use will continue to grow alongside it.

It is not my intention for my choice of words to either ignore the harm that some survivors may experience, to *inflict* harm by way of using terms that may be stigmatizing, or to deny the autonomy of the women who may choose for themselves to practice, and therefore, for the purpose of this research, I intend to use female genital cutting (FGC). Instances where FGC is not used will only be in reference to direct quotes, organizations, and/or initiatives that have demonstrated a difference in preference. Choosing female genital cutting thus accounts for the scope of practices without the risk of inciting any negative connotations that other terms may hold in addition to being in alignment with the terminological preferences of the affected community for which this work intends to serve.

Moreover, when discussing the individuals themselves who have personal experience undergoing some form of FGC, I will be using the term survivor. My reasoning for using survivor is fourfold: 1) survivor has emerged as the preferred term for most community-led organizations; 2) survivor is a non-gendered term and is applicable to a larger scope of gendered identities; 3) survivor is more concise, which helps to improve the overall readability of statements related to individuals who have previously undergone some form of FGC; and 4) survivor centers the individual. In a discussion on the importance of language in discussions around GBV, Kalisch argues, “unlike “victim”, “survivor” shifts the focus onto the individual, emphasizing their resilience rather than their victimization” (Kalisch, 2024, para. 3). This emphasis on resilience is also relevant to the themes associated with theoretical perspectives that underpin this study. However, despite this reasoning, it is necessary to acknowledge that all terms have their limitations. A key limitation of this particular term is that it may not resonate with *all* FGC-affected individuals. This raises the importance of expanding our explanatory frameworks in reference to FGC-affected individuals and FGC discourses more broadly. For

instance, in a discussion on the “survivor” in contemporary culture and public discourse, Orgad (2009) argues for a “need in contemporary public and highly mediated spaces to expand the range of explanatory frameworks through which individuals, especially those experiencing suffering, come to think, judge, and act” (p.132). While beyond the scope of this study, in-depth critical investigations into the use of the term survivor, particularly in relation to FGC, health and illness, gender-based violence, and sexual abuse, will be necessary in order to improve the ways in which we discuss, research, and support individuals

According to the World Health Organization (WHO), the practice of FGC can be broken down into four categories ranging from a minor prick of the clitoris with a sharp implement, to a complete excision of the clitoris and labia and the sewing together of the vulva. The WHO’s classifications include: partial or total removal of the clitoral glans and/or clitoral hood (type 1), partial or total removal of the clitoral glans and labia minora with the potential to leave or remove the labia majora (type 2), the minimization/sealing of the vaginal opening by way of removing the labia minora/and or labia majora and suturing the area sealed with the potential to leave or remove the clitoral glans and/or clitoral hood (type 3), and any other non-medical procedures to female genitalia that could be considered harmful (type 4) (WHO, 2020).

The purpose of this type of classification is to categorize the various ways in which cutting takes place; however, this classification has faced scrutiny from FGC survivors and healthcare providers who have found this classification system to be limiting. This limiting belief is based on the fact that often survivors do not fit neatly into any one of these WHO-designated categories. Additionally, such a classification system would suggest that there is one “universal” guide that professional cutters all around the world follow on how to cut, which is simply not the case. The type of cutting that a woman may experience, and thus the physical outcomes of their

FGC, is as unique as their vulva and any attempts to categorize them differently would fail to accurately reflect individual experiences and bodies.

The extent and variety of complications of undergoing some form of female genital cutting (FGC) is dependent upon the type of cutting a woman has experienced. For instance, women who have undergone type 3 of FGC are more likely to experience long-term health complications due to the fact the labia minora, labia majora, and clitoris are all completely excised, and the remaining tissue is sutured together with the exception of a small hole, less than a centimetre wide, to allow for the passing of urine and menstrual blood (Nyangweso, 2014). Long-term complications may include cysts, abscesses, scarring, injury to the urethra, and painful or unmanageable intercourse (Nyangweso, 2014). In addition to possible physical health complications, survivors may also experience psychological consequences. Such psychological consequences include post-traumatic stress disorder, amnesia, anxiety, concerns around body image and gender identity, depression, and mental blocks related to sexual intercourse that may result in difficulties reaching orgasm (Schrijver et al., 2016, p.270).

In 2006, Berggren et al. interviewed Sudanese women regarding why they underwent FGC (specifically infibulation) to identify whether the women viewed themselves as victims or beneficiaries of the practice. Based on researchers' collection of narratives they noted three themes: pressures to succumb to sociocultural norms, struggles to manage traditional practices while simultaneously desiring change, and a sense that they held little influence in the fight to discontinue FGC.

Many of the women interviewed emphasized the practice's believed benefits of purification and beautification of their genitalia – arguing that FGC represented one's sexual restraint in contrast to uncut women who were viewed as being hypersexual (Berggren et al.,

2006, p. 29). This perceived hypersexuality was then said to influence a woman's marriageability as it would reflect poorly on her family (Berggren et al., 2006). This was observed in the women's discussion around family involvement in FGC, whereby the women interviewed shared complaints of the immense pressure from older female family members.

However, based on their own personal experiences, the women interviewed determined that had they not previously undergone infibulation, that they would be in better health and their sex lives would have likely improved (Berggren et al., 2006). In their view, undergoing FGC resulted in lifelong health complications, which ultimately impacted their ability to enjoy sexual intercourse. As a result, the women interviewed stated that they would not have their daughters infibulated – with some going as far to not wanting their daughters to experience any form of cutting despite the societal pressures discussed.

This sentiment was mirrored in a 2000 study conducted in Canada and the USA amongst 17 circumcised Somali women. Khadija et al. interviewed women to identify how to improve FGC prevention and intervention attempts by assuring they are more culturally competent. During these interviews, women described their parents reasoning for having them undergo FGC – emphasizing the importance of the practice to Somali culture (Kahdija et al., 2000). However, when providing their own perspectives on FGC, the women were unanimous in their desire to see the end of the practice. This end, they hoped, would come as a result of educational campaigns rather than through criminalization, as criminalization was considered to result in secrecy that would eventually lead to the practice's continuation. This exact phenomenon of continuation was observed in Kenya amongst the Maasai and Samburu in Graamans et al.'s community study, which looked at these groups' perspectives on FGC. According to Graamans et al. (2019), criminalization of FGC in Kenya has not only led to the continuation of the practice



in secret, but also to the practice being performed on girls of much younger ages than previously recorded (p. 80).

### **Legal Framework of Female Genital Cutting**

The long list of potential physical and psychological consequences to female genital cutting (FGC) have contributed to the practice's criminalization on an international scale. After decades of repeated calls to action from various human rights groups and feminist organizations across the globe that sought to bring an end to FGC, the practice was finally deemed in violation of human rights and as of 1997, FGC has been prohibited in Canada. Exploring this prohibition of FGC is relevant to this project's aims for three main reasons. Firstly, the matter of legality influences the type of language used when discussing FGC, which affects the way surgical interventions pertaining to FGC are marketed, managed, and thought about in Canada. Secondly, the history of the practice's criminalization can influence survivors' willingness and degree of comfortability in discussing this topic within a health care setting. And, lastly, analyzing Canada's Criminal Code helps to differentiate between medically "acceptable" genital cutting and genital cutting performed for nonmedical reasons.

The Interagency Statement on Eliminating Female Genital Mutilation published in 2008 is an example of using this type of language in stance documents. The Interagency Statement on Eliminating Female Genital Mutilation is a shared statement put forth in collaboration with the following organizations: OHCHR, UNAIDS, UNDP, UNECA, UNESCO, UNFPA, UNHCR, UNICEF, UNIFEM, and WHO. The statement calls for the international community to maintain the rights of girls and women and to bring about the end of FGC as a practice. Authors of this statement emphasize that FGC as violation is more likely to encourage national and international

advocacy groups to pursue the practice's abandonment (p.22). Even though the statement acknowledges the negative associations with the word "mutilation" it maintains that it's use is important in terms of advocacy (p.22). Still Cook et al. (2002) argues, "this [female genital mutilation] is not a neutral description but is a means of condemnatory advocacy" (p.282).

What this usage fails to consider are individuals who do not consider themselves to be "victims of mutilation" or that their bodies should be viewed as "mutilated". Persistence in using this term can come across as discriminatory and stigmatizing (Vissandjée et al., 2014). It is important that we differentiate between the intent of the language we use and the actual impacts of its usage (Vissandjée et al., 2014). Statements describing the practice as "mutilation", such as those in the Interagency Statement, may intend to convey the severity of FGC, but in the process the choice of words may negatively impact those they wish to help through stigmatization. This can similarly be observed when we take a look at these international organizations' stances and the long road it has taken to achieve an agreed upon position, categorization, and mandate.

Presently, the act of female genital cutting (FGC) is recognized as a human rights violation (World Health Organization, 9). Laws and regulations reinforce this stance at the international, national, and local levels (Boyle & Corl, 2010). The specific rights the practice is stated to violate include: the principles of equality and non-discrimination on the basis of sex; the right to life when the procedure results in death; and the right to freedom from torture or cruel, inhumane or degrading treatment or punishment (World Health Organization, 9). Although the act of causing bodily harm has long been considered a crime, FGC was initially difficult to deem unlawful due to its culture associations and significance (Cook et al., 2002).

Culture was viewed as something to be preserved and is protected under the United Nations Educational, Scientific, and Cultural Organization (UNESCO) mandate, which dictates that all human beings have a right to participate in cultural life (World Health Organization, p.10). However, this is subject to certain conditions whereby if the cultural freedom is believed to violate the freedom and protection of others within society it may not be considered justifiable, as is the case with FGC (World Health Organization, p.10).

By the mid 1970s, attention on FGC continued to grow at the international level, this time from western feminists (Boyle & Corl, 2010). Western feminists argued that FGC was the result of a culture of patriarchy and that the practice was in direct violation of the right to non-discrimination based on sex. This stance caused an upset amongst African women in policy who found this type of argument to be more divisive than it was unifying in the sense that they were the targets of Western feminist interventions. To counteract concerns of cultural discrimination and accusations of patriarchal influence, the United Nations decided to take a position based on health (Boyle & Corl, 2010). According to Boyle and Corl (2010), “international actors portrayed medicine as acultural and apolitical<sup>2</sup>, and, because health problems are a universal concern, this basis for intervention did not appear to be singling out African nations for reform” (198). Therefore, the practice of FGC was determined to be in violation of a person’s right to the highest attainable standard of health (World Health Organization, 2010). This approach to FGC was much more quickly accepted, both by political decision-makers as well as community members, in terms of justifying local interventions and international prevention campaigns (World Health Organization, 2020).

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<sup>2</sup> I recognize that despite international actors’ attempts to portray medicine as acultural and apolitical, that medicine, and health more broadly, is inherently political and cultural.

In 1997, the World Health Organization, in collaboration with the United Nations Children's Fund (UNICEF) and the United Nations Population Fund (UNFPA), released a shared statement against the practice of FGC (WHO, 2020). This international response was founded upon the years of calls to action to raise awareness and garner attention towards an ending of FGC. Since that time, 26 African countries and 33 other countries that are home to immigrant populations, have instituted laws and regulations against FGC (WHO, 2020). For the purpose of this research, we will now look to Canada more explicitly and how international human rights laws have influenced our country's political position and management of FGC.

Since 1997, Canada's stance has aligned with that from the World Health Organization, World Medical Association, and the International Federation of Gynaecology and Obstetrics (Vissandjée et al., 2014, p.3). When Canada's criminal code was updated, FGC was added under section 268 for aggravated assault under subsection 3, whereby the excision, infibulation, or mutilation of an individual's labia and/or clitoris was criminalized (Huston, 2000; Section 273). In an evaluation of Canada's response to FGC, Packer et al., (2015) stated, "under the code, it is prohibited to aid, abet or counsel such assault and to interfere with genitalia for nonmedical reasons" (E188). The code goes on to include the criminalization of sending a child outside of national borders for the purpose of having FGC performed (Packer et al., 2015). If someone is found guilty under one of these offences, they could face up to 14 years behind bars and/or receive a fine (Packer et al., 2015).

Packer et al. (2015) emphasizes the importance of not assuming that because there have yet to be any prosecutions under this code that it means that FGC is not being performed in Canada. Canada has an exceptionally high rate of international migration – with international

migration accounting for 92.0% of Canada's overall growth in the third quarter of 2024 (Statistics Canada, 2024). This includes immigrants and refugees from countries with the greatest prevalence rates of FGC, such as Egypt, Eritrea, Sierra Leone, and Somalia (Packer et al., 2015). The reality of low rates of prosecution in Canada may ultimately come down to the fact that it can be extremely difficult to prosecute. Often young women and girls are reluctant to come forward if they have experienced FGC, or are at risk of undergoing it, out of fears that they may implicate their parents in a crime (Packer et al., 2015). In addition to fears around potential family involvement, if the cutting occurs abroad, it can be even more challenging to track, which further decreases the likelihood of prosecution (Packer et al., 2015).

Under this legal framework, Canadian physicians and other healthcare professionals hold a crucial responsibility to report if they believe an individual has experienced some form of FGC or is at risk of undergoing it (Perron & Sennikas, 2012). In addition to the Society of Obstetricians and Gynaecologists of Canada, who have released a national policy statement, some provinces have released their own statements. The current provincial Canadian Medical Organizations with FGC statements include: the College of Physicians and Surgeons of British Columbia, the College of Physicians and Surgeons of Ontario, the College of Physicians and Surgeons of Alberta, the College of Physicians and Surgeons of Manitoba, Collège des Médecins du Québec, and the College of Physicians and Surgeons of Nova Scotia (Huston, 2000). The majority of these statements are brief, ranging from a few short sentences to a maximum of a handful of paragraphs, and typically include a link to position statements made by other national medical organizations and/or the criminal code.

Within these position statements it is also common to briefly acknowledge potential requests for re-infibulation and how to navigate them. Re-infibulation is the practice of re-suturing a survivor's genital tissue post-delivery and can sometimes be requested by a survivor, their partner, or a survivor's family. This is relevant to discussions around the criminal code, which specify under subsection 3 (a) and 3 (b), that genital surgical procedures must improve the physical, reproductive, and/or sexual health of an individual who is at least 18 years old, and that the procedure is performed by a qualified medical professional (Section 273). In these instances, the practice of re-infibulation may be difficult to reconcile. Currently, the policy statement from the Society of Obstetricians and Gynaecologists of Canada (SOGC) strictly states that physicians should deny these patient<sup>3</sup> requests for re-infibulation; however, they also note that it ultimately comes down to the better judgment of the medical professional.

According to the Canadian Medical Association's (CMA) Code of Ethics section, under Responsibilities to Society, Vissandjée et al. (2014) states,

Health professionals must recognise that community, society and the environment are important actors, and the health care professionals are faced with the legal obligation to notify statutory bodies of the occurrence or risk within the host society of FGC, ethical

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<sup>3</sup> The term "patient" is used throughout this dissertation when in reference to medical literature, clinical settings, and physicians' accounts. The social and philosophical underpinnings of the term "patient" are explored by Whyte et al. (2024) in their study on terminological significance for individuals with long-term conditions. Here, Whyte et al. acknowledge the importance of language when discussing interactions between healthcare providers and individuals seeking care. The term "patient" has been criticized for failing to address imbalances of power between providers of care and recipients of care (Neuberger, 1999; Whyte et al. 2024). Additionally, the term "patient" can also portray individuals as passive – patiently tolerating their suffering in wait of an intervention from a medical expert (Neuberger, 1999). As such, by using the term "patient", it is not my intention to contribute to such medical hegemonic discourses, but rather to simply maintain the accuracy of literature referenced and physician participants' accounts in this study. Whenever possible, in all other instances, the term survivor is used in order to centre the individual in their search of care.

considerations of article 41 need to be carefully weighed with their legal requirements to report (3).

This matter of ethical considerations is further highlighted in Askew et al.'s (2016) paper, which explores a repeat call for the complete abandonment of FGC. Here, Askew et al., reflect upon movements which sought to replace traditional forms of FGC with a “symbolic nick” – a small surgical cut that would be performed by medical professionals in healthcare settings in lieu of more culturally conventional forms of cutting (Abdulcadir et al., 2011). According to Askew et al. (2016), “the performance of the ‘nick’ by medical personnel would likely perpetuate the practice through future generations by seeming to legitimise it” (p.619). Therefore, it is important for health care providers to emphasize that there is no medical justification for FGC and physicians are encouraged to recognize the practice as a form of gender-based violence, which violates the rights of women and girls (Askew et al., 2016).

### **FGC and Gender-Based Violence (GBV)**

As outlined above, the practice of FGC is considered a form of gender-based violence. The UNHCR defines gender-based violence (GBV) as violence that is committed against a person based on their sex or gender (UNHCR GBV Toolkit) and is inclusive of any harmful physical, sexual, mental, or socio-economic acts that may cause suffering (Wei et al., 2024, p.2). All people can be subject to GVB; however, some groups are *more* likely to experience violence including women, women of colour, women living with disabilities, and 2SLGBTQQIA+ individuals (Government of Canada, 2022). The effects of GBV can be even more extreme for women who already experience marginalization, racism, and discrimination in their daily lives (Wei et al. 2024).

In Heidari and Moreno's 2016 study, they explore how these experiences of GBV can create a barrier to sexual and reproductive health rights. Due to the fact that GBV is rooted in gender inequality, authors highlight the impacts of disrespectful and neglectful treatment of women in healthcare settings – particularly when it comes to childbirth. According to Heidari and Moreno, this type of GBV is referred to as “obstetric violence” (2016, p.2). Unfortunately, the experiences of FGC survivors who have experienced obstetric violence in Canada is well-documented (Chalmers & Omer-Hashi, 2001).

Chalmers and Omer-Hashi review the accounts of survivors living in Canada in their 2003 book titled '*Female Genital Mutilation and Obstetric Care*'. Here Chalmers and Omer-Hashi recount the experiences of Somali women who had undergone needless and traumatizing caesarean sections solely due to the fact that the performing physicians were uneducated in the proper care and treatment of birthing FGC survivors. At this time, because Canadian physicians were unfamiliar in caring for women that were infibulated or had undergone “type 4” FGC, whereby the labia majora, labia minor, and clitoris were all removed leaving the skin to be sutured back together with the exception of a small hole for urine and menstrual blood to pass through, Canadian physicians were opting for caesarean sections citing “safety precautions” (Chalmers & Omer-Hashi, 2003). However, these procedures were particularly traumatic for the Somali women giving birth as they held certain cultural beliefs that associated hospitals and caesarean sections with death (Chalmers & Omer-Hashi, 2003).

When it comes to these types of practices under the guise of “treatment” or “medical intervention”, Heidari and Moreno argue,



Addressing this form of mistreatment and abuse from a human rights perspective and within a violence against women framework aims to highlight the structural dimension of this violence, increase its visibility, and generate actions from health systems to ensure that all sexual and reproductive health services are provided in a manner that fully respects women's choice, autonomy, and rights (2016, p.2).

The Canadian government has since claimed to have taken a proactive approach in support of anti-GBV initiatives, particularly against cases of violence within healthcare systems. For instance, in a 2022 statement made by Canadian Prime Minister Justin Trudeau, Trudeau's government announced an average of \$1.4 billion annual investment from 2019 to 2023 to "support the health and rights of women, children, and adolescents around the world through global organizations and Canadian and international non-governmental organizations" (Prime Minister of Canada Justin Trudeau, 2022). As part of this annual \$1.4 billion investment, \$700 million per a year is said to be allocated for sexual and reproductive health and rights more specifically (Prime Minister of Canada Justin Trudeau, 2022).

The discussion of Canadian investment in projects against GBV is also relevant to examinations of FGC-related organizational funding and governmental support. Since the introduction of the zero-tolerance approach to FGC by the United Nations, FGC-related organizations have adopted it into practice (O'Neil et al., 2020). In their article on rethinking anti-FGM zero-tolerance policy, O'Neil et al. argues "this is not merely a moral and legal issue but also an economic one because awareness raising activities, which are mainly run by non-governmental organizations, are funded only by international institutions if they apply the zero-tolerance approach" (2020, p.267). In Berer's (2015) study on the history and role of criminal

law in anti-FGC campaigns, Berer offers an example of Ugandan programs and organizations, which were funded so long as they upheld these anti-FGC positions. For instance, when describing the Reach Programme and Reproductive Health Uganda, Berer (2015) states, “[they] were making money only insofar as they were funded by UNFPA to “sensitise communities against FGM through elders’ associations, community meetings, in schools, and on radio stations” (p.150). Unfortunately, in this case, petitioners for these programs and organizations experienced backlash from community members who argued their anti-FGC position was simply a means of profiting from campaigns against FGC (Berer, 2015, p.150).

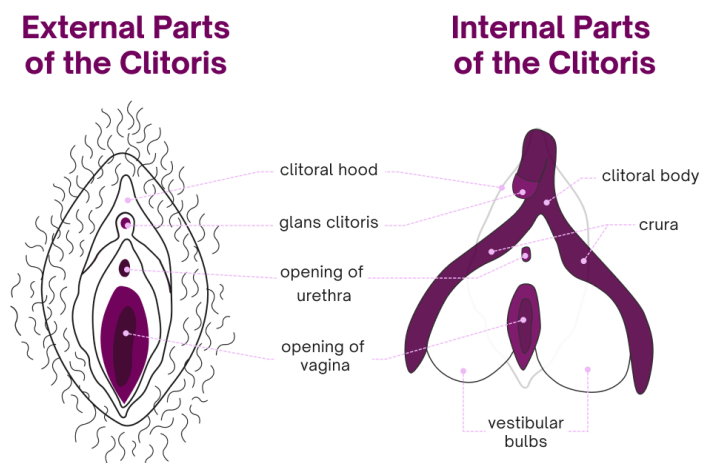
When looking to Canada, the Governmental Department for Women and Gender Equality (WAGE) is one of the largest financial backers of FGC-related organizations in Canada. For example, in February 2022, when issuing a statement on the International Day of Zero Tolerance for Female Genital Mutilation, the Prime Minister of Canada, Justin Trudeau stated, “Canada is a strong advocate for gender equality and the empowerment of women and girls at home and abroad. Last August, the Government of Canada announced \$530,000 in funding toward End FGM Canada Network’s Joining Hands Project, to address systemic discrimination against girls at risk of FGM/C and survivors” (Prime Minister of Canada Justin Trudeau, 2022). Therefore, in order to receive substantial financial support to fund FGC-related supports, programs, and initiatives for survivors, it is imperative that these organizations align with the zero-tolerance approaches and anti-FGC governmental stances more broadly.

### **The Clitoris and Clitoral Restoration Surgery (CRS)**

The terminology used to describe clitoral restoration surgery (CRS) is varied and includes several terms such as clitoral reconstructive surgery, clitoral restoration, genital reconstruction,

clitoral transposition, or clitoral re-exposition. The preferred terminology used depends on individual preferences and I find that even my own terminology preferences have evolved over the course of this investigative journey. These differences in one's terminology preferences stem from the reality that surgeons are not truly constructing something new but are rather restoring what it already there. Urogynecologist and cosmetic gynecologist, Dr. Seifeldin explains, "because most erectile structures are not excised, healthy women with FGM can reach orgasm and experience satisfying relationships, since more of the clitoris remains" (2016, p.1) – it may be under scar tissues, but it is still there, just beneath the surface.

This is why it becomes increasingly important to have a workable understanding of clitoral anatomy before continuing with descriptions of this procedure. The clitoris is a much larger sexual organ than one might originally think based on what is often visible externally. What we see outside the body is only a small portion, approximately three quarters of an inch to an inch of the clitoral glans. The entire clitoris, so including what we find internally, can measure anywhere from 3.5 to 4.35 inches long and 2.5 inches wide and hosts more than 10,000 nerve fibres, which is a significant increase from pre-2023 estimates that identified 8000 nerve fibres (Uloko et al., 2023).



*Figure 2. Clitoral Anatomy (Source: Natural Cycles, 2024)*

In Pauls' article on the anatomy of the clitoris and the female sexual response, Pauls describes the clitoris as, "the most pivotal structure for female sexual pleasure" (2015, p. 378). As discussed in the study's introduction, the clitoris has been identified, celebrated, demonized, forgotten, and "rediscovered" countless times over hundreds of years; however, it has only very recently been described with any anatomical accuracy (Pauls, 2015; Stinger & Becker, 2010; Charlier et al., 2019). With the help of scientific advancements in anatomical dissection and magnetic resonance imaging (MRI), researchers and physicians have been able to accurately map out this sexual organ's composition and determine its dense innervation (Pauls, 2015).

Anatomically speaking, the clitoris is comprised of seven main components which include: the glans clitoris, the prepuce/clitoral hood, suspensory ligament, body or corpora, crura, root, and bulbs (Pauls, 2015, p. 377). Of these seven main components, only two parts are external: the glans clitoris and the clitoral hood. The fact that the majority of components that make up the clitoris are internal, and thus are not typically visible, has greatly contributed to false beliefs regarding the sexual organ's form and intended purpose.

An understanding of the anatomy and physiology of the clitoris, along with the factors that have contributed to its misrepresentations, can help us to better understand why some survivors of FGC might want to undergo CRS and can offer certain insights into a few of the desired outcomes they may hope to achieve. For instance, survivors who are unaware of the internal components of the clitoris and complex nerve supply may be surprised to learn that they still have functioning nerve endings beneath their scar tissue.

When it comes to clitoral restoration as a relatively recent medical development – very few studies have been conducted to evaluate the postoperative outcomes. In 2015 Abdulcadir et al. performed a systematic review on the surgical procedure and determined that FGC survivors electing to undergo CRS should be cautious when making their decision as limited evidence was available. Upon identifying these gaps, Abdulcadir et al. (2015) called for an increase in studies to evaluate the effectiveness of the procedure, identify the benefits patients might receive, and the long-term outcomes. Out of the current available studies, the majority come from Dr. Pierre Foldès.

In the late 1990s, French surgeon Dr. Pierre Foldès, in collaboration with his colleague Jean-Antoine Robein, developed clitoral restoration surgery (CRS) in order to address any urological, obstetric, and/or vulvar pain experienced by women with some of the more extreme forms of female genital cutting (FGC) as part of a humanitarian pilot project in Burkina Faso (Jordal et al., 2019). Following the success of CRS within a humanitarian context, Foldès began offering it in France in the early 2000s as a reparative option for both immigrant FGC-affected women living in France who had experienced FGC prior to immigrating to France as well as French women who had experience FGC in France (Foldès et al, 2012). In a cohort study beginning in 1998 and ending in 2009, Foldès performed reconstructive surgeries on 2938

patients (Foldès et al., 2012). Foldès et al. state that, “expectations before surgery were identity recovery for 2933 patients (99%), improved sex life for 2378 patients (81%), and pain reduction for 847 (29%)” (Foldès, 2012, p. 134).

The surgery itself can be performed in 30 minutes or less, and while the use of local anesthesia is an option, performing physicians will often opt for the use of general anesthesia as a preventative measure against re-traumatizing survivors who underwent FGC without any anesthesia (Schrijver et al., 2016, p. 270). During CRS the performing surgeon will remove the scar tissue, make a deep incision to draw the clitoris out, and then suture the exposed glans into place while preserving the sensory nerve endings (Foldès et al., 2012). In their study exploring the impacts of post-traumatic stress disorder amongst FGC survivors that chose to undergo CRS, Abdulcadir et al. (2017) describe the following reparative technique in detail stating,

We resected the cutaneous scar covering the clitoris with scissors and dissected the clitoral stump to the upper edge of its elbow with electrosurgery. We removed the subcutaneous periclitoral fibrosis and sectioned the suspensor ligament of the clitoris remaining near the periosteum of the pubic symphysis to maintain the neurovascular pedicle of the clitoris intact. Once the healthy body of the clitoris was released, we reconstituted a healthy new glans by two lateral continuous sutures of Monocryl 3.0 and a superior anchorage stitch fixing the neoclitoris to the two bulbocavernous muscles. Hemostasis was performed with electrosurgery. On the upper part of the neoglans we created a prepuce of the vulvar skin. (p. 372)

Detailed descriptions of the variety of complications some survivors may experience as a result of undergoing CRS are significantly lacking (Abdulcadir et al., 2017). Further research is needed in order to gain a greater understanding of why certain survivors may experience some

complications while others may not. However, a study conducted in Switzerland observed “infections, wound dehiscence, keloids, hyperesthesia of the clitoris, and decreased sexual function” all as possible complications that survivors may be at risk of experiencing as a result of undergoing CRS (Abdulcadir et al., 2017, p. 374).

In addition to addressing physiological issues, CRS may also provide a surgical option to address some sexual and/or mental issues that can impact FGC-affected women. However, while this procedure may enable FGC-affected women to be clitorally orgasmic, it is not a promise of clitoral orgasms (Jordal et al., 2019). This reinforces the importance of a multidisciplinary approach to the care of survivors seeking to undergo CRS in order to manage survivors’ hopes and expectations. While this surgery has the potential to improve the sex lives of survivors, it is not simply a matter of the physical changes through surgery. Sexuality itself is exceedingly complex and often relies as much on mental stimulation as physical. Therefore, any physical changes that occur will have to be taken into consideration in combination with how those changes influence shifts in survivors’ mindsets and/or perceptions of themselves.

Foldès et al. (2012) state, “sexual pleasure varies from one sexual partner to another, and this could therefore be another major limitation. The complexity of the sexual dysfunction that can be associated with female genital mutilation [sic] underlines, for us, the need to systematically offer sexual therapy for patients” (p. 139). This is particularly important to note, as a significant number of studies have been conducted regarding the perceived sexual dysfunction survivors may experience due to having undergone some form of FGC. However, what researchers have found is that some survivors are not necessarily any more likely to experience sexual dysfunction from a physiological perspective (Catania et al., 2007; Jordal et al., 2019; Schrijver et al., 2016). For instance, in a study on pleasure and orgasm in women with

FGC, Catania et al. (2007) note that the external clitoris is only the “top of the iceberg” and that some survivors are still able to reach orgasm through vaginal/internal clitoral stimulation (p.1673). Here, instances of sexual dysfunction were more so linked to cultural perceptions of pleasure and limited sexual education (Catania et al., 2007, p.1676). Therefore, such findings emphasize the importance of the psychosexual role and how CRS, in combination with different therapeutic measures and/or a holistic approach, could positively impact survivors’ sex lives and issues around body image.

### **CRS in the Context of Other “Elective” Female Genital Surgeries and Medical Terminology**

While clitoral restoration surgery (CRS) as a reparative option for survivors is a relatively recent phenomenon within the medical community, surgical procedures for women and girls’ genitalia are not. Such surgeries are often conceptualized as reparative in nature, for instance operations on girls and women with congenital adrenal hyperplasia (CAH) are performed with the intent to return, what is deemed as “physiologically abnormal genitalia”, back to “normal” from an anatomical perspective (Johnston, 2012). Justifications for cosmetic genital surgeries are comparably founded on the premise that there is a “right” or “normal” way for women’s genitalia to be both in appearance and in function (Davis, 2002).

In a discussion on labiaplasty, which is a surgical procedure where a woman’s labia tissue is trimmed, and/or fat is removed from another area of the woman’s body and inserted into the labia to plump it, Davis (2002) describes the motivational factors that encourage women to undergo cosmetic genital surgery (p.7). In combination with the influence of media and pornography, Davis (2002) highlights the issue of medical supremacy noting, “bringing the



authoritative language of medical science to the aestheticization of the vagina is one keyway to trigger such anxiety” (p.7). Such language legitimizes women’s fears, concerns, and/or anxieties regarding their genitalia and leads them to believe that something is wrong with their bodies if what they see in the mirror deviates from the medical doctrine of “normalcy”. These concerns can further exacerbate any pre-existing psychological or sexual issues whereby women believe that undergoing surgery is the only solution to the problems that they feel they are experiencing (Berer, 2010, p.9).

Like the pervasive authoritative nature of medical jargon, our choice in words holds significant power and plays a major role in how we come to understand things. Moving forward, the way in which clitoral restoration surgeries are defined within the medical context will influence not only how the surgeries and procedures are viewed, but also in how individuals who seek to undergo these surgeries are viewed as well. In the case of clitoral restoration surgeries, this procedure presents a bit of a categorical dilemma as its purpose changes with increased learning of its potential physical, mental, and sexual outcomes.

As previously discussed, CRS was initially developed in order to alleviate any pain survivors may experience from having previously undergone some of the more invasive forms of female genital cutting (i.e., clitoridectomy and/or infibulation). In addition, although the surgery does not promise clitoral orgasms, it does maintain the possibility of making survivors clitorally orgasmic and boasts its ability to return external genitalia back to physiological definitions of “normal”. This recategorization from a pain-relieving procedure to one that may enhance women’s sex lives and/or body image will need to be considered in the development of future policies.

Currently, CRS is considered an elective surgery. In McCarthy and Finkle's (1978) study exploring second opinion elective surgery programs, the authors define elective surgery as "non-emergency procedures" (p.985). Although CRS may help to address pain – it is not performed with the intent of saving a woman's life, nor is anyone forcing a woman to undergo the procedure; thus, such surgeries are categorized as "elective". However, external pressures from societal norms of idealized bodies can hold great influence over one's personal desire to undergo "elective" surgeries. In a comparative study between acceptance of female genital cutting versus genital cosmetic surgery procedures, Johnsdotter and Essén (2010) highlight several factors that may influence women to "fix" their bodies citing, "victims of patriarchy, of the beauty industry, of the pressuring ideals of today, or their own inner insecurities" (p.32). Such procedures extend well beyond the realm of genital modification to include breast augmentation, gluteoplasty, liposuction, and more. Many of these elective procedures are marketed towards women to "help" them overcome an insecurity that society instilled in them to begin with. Therefore, when women's bodies are scrutinized and pressured by society to modify their appearance it does raise the question of how truly *elective* "elective" surgeries are.

Latham (2010) highlights concerns around autonomy in patient decision-making when it comes to cosmetic surgery in the United Kingdom stating, "autonomy can be taken to refer to the ability of patients to make their own fully informed decisions about their treatment, necessitating information about choice of procedures, standards of treatment, risks and possible outcomes, and the ability of the health professional to carry out the procedures. A patient's physical integrity is respected in this way" (p.49). In this view, patients maintain the right to formulate an autonomous decision free from coercion (Latham, 2010, p.49). However, in this example, Latham is preoccupied with coercion from medical professionals and/or salespeople from clinics

in the United Kingdom who are likely to profit from coercing potential patients into undergoing surgery (Latham, 2010, p.49).

### **Experiences of FGC Survivors and the Perceptions of “Normative” Bodies**

These issues around body image and concerns of altering one’s appearance to meet some type of “ideal” largely stem from perceived deviations from the idealized “normal” body. However, an individual’s perception of what constitutes normal can vary greatly depending on the biomedical or sociocultural context in which it is applied. For instance, according to the American Heritage Medical Dictionary (2007) “normal” is defined as, “functioning or occurring in a natural way; lacking observable abnormalities or deficiencies”. Within medicine, certain parameters are assigned to manage and calculate pathology (Banerjee, 2011). Deviations from these parameters, either above or below these “healthy” ranges, are then flagged as abnormal. Therefore, under this biomedical definition, a survivor’s external genitalia would be viewed as “abnormal”.

However, a biomedical definition of normality is but one definition of normal. Another definition of “normal” is “that which is most common”. For this conceptualization of “normal”, the frequency of which something occurs is an indicator of normalcy. Koeslag (1993) provides the example of shortness of breath and usualness to explore the idea of that which is “normal” is that which is most common (p.47). For instance, if you live at the top floor of a 10-story apartment building, it is likely that you will be winded climbing up multiple flights of stairs to reach your apartment. However, if you find yourself short of breath after bending down to tie your shoes it may be a sign that you should seek medical advice. In this example, it is much more common to experience shortness of breath after engaging in moderate to intense physical

activity compared to becoming winded by performing mundane tasks that should not require significant physical exertion. A deviation from this “usualness” would be considered “abnormal”, and thus justify consulting a physician to discuss potential interventions.

However, even the use of medical interventions has impacted our perceptions of what is “normal” in this case. Rudnick (2000) emphasizes the commonness of certain disabilities and how these variants can be considered “normal” based on their frequency of occurrence. For example, Rudnick argues, “disability presents itself as a pathological only when self-organization is impaired and there is a resulting handicap” (p.3). Therefore, with the development of new medical technologies that change the lives of people living with disabilities, so can they change our understandings of what is “normal”.

These changes in our understandings can also apply to sociocultural norms. In this instance, the understanding of “normal” as “a cultural norm” emphasizes the social implications that contribute to one’s perception of health, illness, and disease (Harris et al., 2015). In this context, what is viewed as “normal” is socially constructed and influenced via any number of individual, social, cultural, economic, and/or environmental factors (Harris et al., 2015, p.178). Due to the fact that this conceptualization is socially constructed, many different groups may develop their own unique understandings of what is “normal”. Therefore, this concept of “normal”, meaning to conform to a cultural norm, is challenged by our own cultural differences as people. Harris et al. (2015) provides an example of this from their study on the sociocultural constructions of obesity and excessive weight among African American women. Harris et al. found hair to be one of the main determinants of whether or not an African American woman was going to engage in physical activity. For many African American woman, taking care of

their hair can be both expensive and time consuming; therefore, African American women were found to avoid physical activity if it meant that they would run the risk of ruining their hair (Harris et al., 2015, p.178).

In addition to hair, Harris et al. (2015) also emphasized other sociocultural constructions that impacted African American women's health, the second being ideal body image. According to Harris et al. (2015), "larger body sizes for women are often socially constructed to symbolize health, beauty, sexual attractiveness, wealth and being a good mother/wife" (p.180). These ideals influence various cultural and ethnic groups' perceptions and understandings of what it means to be obese or overweight. This is particularly relevant when we consider scientific measurements of obesity or overweight, such as the body mass index (BMI), which according to Harris et al. (2015), "impose a "White Body Norm" ideal onto other racial/ethnic groups to whom the measure may not adequately apply" (p.181). Therefore, even when considered within a sociocultural context, the way in which the term "normal" is applied can often shed light upon what, or in some instances *who*, society values (Banerjee, 2011).

When words such as "normal" can convey a multitude of meanings it is important that their users define them appropriately. The act of defining not only provides clarity, but also justification when the usage holds real life implications for those in reference to "being normal". This is the case for FGC survivors living in Canada. Bodies of FGC-affected women are medicalized and criminalized through policies and regulations that imply they are not "normal". These categorizations have financial, legal, and cultural impacts on women's lives.

According to Caïta et al. (2020), from a perspective of comparison, deviations from what is "normal" can justify "medical intervention, health insurance policies, and public health

measures” (1). Under the Canada Health Act (CHA), the act specifies that, “all eligible residents of Canada have reasonable access to medically necessary services on a prepaid basis without direct charges in the point of service for such services” (Asanin & Wilson, 2008, p.1272). However, similarly to the use of “normal”, the act fails to define what the CHA implies by “medically necessary”. This failure to define “medically necessary” has resulted in inconsistencies cross-provincially and territorially as to what is and is not covered under the CHA and increases the risk of perpetuating pre-existing health inequities in Canada (Chowdhury & Chowdhury, 2018).

By providing a literature review of key themes associated to the research aims of this study, this background chapter has helped to situate CRS within the relevant larger contexts. In order to further situate the themes of this study, the next chapter will outline the project’s theoretical perspectives. As described here, the introduction of CRS in Canada is much more complex than previously conceived and holds real implications at the individual, interpersonal, and institutional levels. As such, in order to accurately reflect these interacting factors, it is important that a theoretical lens is applied that can account for this complexity within the study’s analysis. Therefore, Chapter Three – Theoretical Framework, introduces the study’s theoretical perspectives, offers justification for their application, and provides an outline for how it should be understood in relation to the study’s aims.

### **Chapter Three – Theoretical Framework**

In order to account for the complexity of CRS experience in Canada, three complementary theoretical perspectives have been chosen. These theoretical frameworks include feminist intersectionality theory, complexity theory, and multisystemic resilience. Feminist intersectionality theory is explored first – highlighting the role of feminist research in attending to the voices of marginalized groups particularly within the context of health research. Complexity theory is then introduced as a complementary approach to feminist intersectionality theory through its larger systems perspective. According to McGibbon and McPherson, when combined, these two theoretical perspectives “create a view into the complex landscape of inequity” (p.77). This issue of inequity is inherently linked to discussions around adversity, which is a key component to multisystemic resilience. As a result, multisystemic resilience offers a more in-depth understanding of how each of this study’s key demographics (i.e., survivors, healthcare providers, and FGC-related organizations) confront, adapt, and overcome instances of adversity related to the introduction of CRS and provision of FGC-related care more broadly in Canada.

#### **Intersecting Perspectives**

##### ***Feminist Intersectionality Theory***

In the literature review, several factors were explored related to FGC-survivors’ experiences navigating Canada’s health care system and emphasizing their unique health care needs – especially in relation to the development of a newly elective genital surgery here in Canada. Stories of FGC survivors are similarly explored in Kiguwa’s investigation of women’s gendered experiences, here Kiguwa (2019) shares two narratives, the content of which center on the practice of FGC and survivors’ personal accounts. According to Kiguwa, “the autonomy that

women have over their own bodies and the violence that may be enacted against these bodies have inspired much theorising, research, and policy framing the world over” (p. 222). It is through both of these stories, that Kiguwa emphasizes the issue of the autonomy of women’s bodies, and argues, “is of central concern to much feminist work” (p. 222).

The purpose of feminist research, as described by Kiguwa (2019), is “to attend to women’s marginalised and often silenced voices, not just in the social world, but also in the production of knowledge” (p. 255). This issue of marginalization is relevant to investigations of CRS, as the procedure is intended for FGC survivors who, within the context of Canada, are most commonly immigrant women of racialized backgrounds who have experienced a gendered sociocultural ritual that affects their sexual anatomy (Nwoke & Leung, 2020).

According to Nwoke and Leung (2020), “compared to any other group, immigrant women from racialized backgrounds, including recent immigrants, continue to experience the most significant challenges in accessing healthcare, ultimately leading to poorer health outcomes than their non-immigrant counterparts” (p.1447). An individual’s immigration status, ethnicity, and gendered reality influences their ability to, and experiences of, accessing and navigating a healthcare system, particularly when that system is intended for a privileged group (i.e., white, wealthy, educated, male) (Collins, 1989). All of these factors combine to impact a survivor’s experience when it comes to accessing CRS and related treatment options, which therefore necessitates a theoretical perspective, such as feminist intersectionality theory, to support an understanding of each of these factors and how they intersect.

There is no universally agreed-upon definition of feminist intersectionality theory (Hankivsky et al., 2009; Collins, 2017); however, there are some key principles that can be identified within. For instance, Collins and Bilge (2020) identify six core ideas within



intersectionality, which include: “social inequality, intersecting power relations, social context, relationality, social justice, and complexity” (p.35). According to Collins and Bilge, scholarly interest in intersectionality has grown within healthcare research due to “intersectionality’s focus on complex social inequalities” and this framework’s capacity to “shed light on health and illness” (p.48). Similarly, McGibbon and McPherson state, “feminist intersectionality theory provides a comprehensive foundation for interrogating the multiple ways that SDH [social determinants of health] shape women’s health across the lifespan” (p.63). As a demographic, the health and well-being FGC survivors in Canada is greatly affected due to the barriers in care they experience (Nwoke & Leung, 2020). By employing an intersectional feminist lens to the study of CRS, it allows for a deeper understanding of these complex challenges in accessing CRS, affording the procedure and associated treatment options, and receiving culturally safe and compassionate care.

### ***Complexity Theory***

In order to further account for this complexity, in addition to feminist intersectionality theory, this study also applies complexity theory as a complementary theoretical lens to account for each of these intersections interacting within the frameworks of a larger complex system. McGibbon and McPherson (2011) argue, “although feminist intersectionality theory allows us to envision the ways that oppressions come together to compound women’s struggles, it may be argued that it falls somewhat short of describing the interactions within this web of larger systems, particularly health and social service systems” (p.72). To illustrate their argument, McGibbon and McPherson provide the example of a young girl named Marya who lives with chronic illness and cannot afford transportation to her medical appointments (76). Marya is raised in a low-income household with minimal education and experiences several challenges as

she attempts to navigate the intersection of these various social determinants of health. These challenges are then further exacerbated by the reality of poor government funding, which has resulted in substandard public transport leading to geographic barriers. Additionally, a shortage of public policy to provide universal access to medication leads to high costs of over-the-counter prescriptions (McGibbon and McPherson, 2011). Therefore, McGibbon and McPherson argue that these systemic oppressions (e.g., classism, racism, sexism) then “operate *within* a complex public service systems” (p.76). In terms of FGC, while intersectionality is interested in the characterization of different axes of marginalization, complexity theory adopts a system approach to further situate the experiences of FGC survivors in Canada. This is where the addition of a multisystem perspective makes for a complementary approach to the established feminist lens to strengthen the overall analysis of CRS in Canada.

Physicist Fritjof Capra (1975) is argued to be one of the original theorists in the conceptualization of complexity theory. In Capra’s conceptualization, natural and social phenomenon were described within the context of a complex web of systems, all of which are interconnected. This conceptualization goes on to suggest that in order to develop an accurate understanding of a system as a whole, one must explore the individual parts of which that system is made (McGibbon & McPherson, 2011). This concept was later expanded upon to make a distinction between a system and the system’s environment (Walby, 2007). This distinction was developed in order to negate any rigidity associated with the “parts as a whole” conceptualization and to account for the fluidity of a system’s ability to change and grow over time. In this view, according to Walby (2007), “each social system (whether economy, polity, violence nexus, or civil society) takes all other systems as its environment. Likewise, each set of social relations (e.g., gender, ethnicity, class) is a system, taking all others as its environment” (p.458). The

expanding interpretations of complexity theory have garnered attention amongst multiple disciplines as its breadth of applicability has enticed multi- and inter-disciplinary researchers alike (McPherson, 2008).

To illustrate the relevance of a larger complex systems perspective to FGC-related research we can look to the economic impacts of FGC globally. When the rates of women and girls at risk of undergoing FGC are calculated, we can view how FGC and its related health complications are capable of impacting the larger global economic system. For instance, between 1990 and 2012, Goldberg et al. (2012) determined that in the United States alone, the number of women and girls at risk of undergoing FGC rose by 224%. Based on data collected from 27 countries, the World Health Organization (WHO) determined that the economic costs of treating FGC-related health complications accounts for 1.4 billion USD a year (WHO, 2016). If prevalence rates remain unchanged over the next two to three decades, this amount is expected to increase to 2.3 billion USD annually (WHO, 2016). The results of these external factors, such as economic impacts (e.g., costs to receive FGC-related treatment) in addition to legal pressures (e.g., anti-FGC laws) can influence the internal dynamics of the practice. Therefore, McGibbon and McPherson (2011) argue that, “local, regional, national, and international systems of inequity are inextricably linked and cannot be ameliorated without an analytic focus on how these complex systems act together in a complex web of larger systems” (p.70). Analyzing the intersections of oppression as they operate within a larger complex system will not only deepen our understanding of the issue at hand, but also enhance our ability to institute change at larger health, social, and economic levels.

In a 2018 study on CRS in Sweden, Jordal et al. argue, “FGC and CR [clitoral reconstruction] have medical, social, gendered, and psychosexual implications” (p.703). Many of these implications are the result of the intersection of oppressions that survivors face. In Canada, survivors are likely to face challenges based on their race, gender identity, immigrant status, level of education received, and socioeconomic position. All of these challenges, at varying degrees, will influence an FGC-affected woman’s ability to access CRS as a reparative option, due to the fact that the larger healthcare system is designed for, and sustained by, more privileged groups (i.e., white, wealthy, educated, male, national). Analyzing the introduction of CRS from an intersecting feminist lens in addition to a larger systems perspective will help to better conceptualize this complexity.

In Jordal and Wahlberg’s review they identify several interconnecting factors that contribute to the complexity of providing quality care for FGC-survivors in Sweden. These challenges exist at the macro/societal level, the exo/institutional level, the meso/interpersonal level, and the micro/individual level (2018, p.94). A key component in the analysis of complex systems is a system’s adaptive capacity (Craig, 2020, p.1758). Holling, one of the founders of resilience theory, defines adaptive capacity as the “capacity of actors, both individuals and groups, to respond to, create, and shape variability and change in the state of system” (Craig, 2020, p.1758). Given the link between resilience and complex systems it becomes ever more important that we define resilience for the purpose of this discussion. By doing so, it allows us to explore how associated notions of adversity, adaptability, and change are relevant to examinations of newly introduced surgical procedures – particularly those that are intended for gendered and racialized populations.

### *Resilience Theory*

Defining resilience can prove challenging given its wide range of applicability within ecological, biological, psychological, and social fields of study (Ungar, 2020). According to Brown (2020), the fact that resilience is well suited across several disciplines speaks to “its theoretical, conceptual, and methodological richness” (p.778). Despite several formulations of resilience, there are some key defining terms that emerge repeatedly, such as adversity, adaptation, and change/transformation. In an exploration of community resilience in a rural Australian community, Buikstra et al. emphasize the variability of resilience definitions but found that the most common denominator when it came to conceptualizing resilience was that it was linked to overcoming adversity (2010, p. 966). Furthermore, when examining this progression of resilience definitions over time, Dahlberg’s (2015) article on conjoining resilience and complexity discourses states, “note the emphasis on adaptation: what makes a complex adaptive system resilient is it’s learning and transformational capabilities, not its ability to merely resist a shock” (p. 545). Therefore, a consistent theme in the progression of resilience definitions has been an emphasis on its complex, interrelated, dynamic qualities, ability to “fluctuate over time”, and link to adversity (Buikstra et al., 2010). This emphasis on adversity and perseverance is especially important in terms of helping to differentiate resilience from other similar and complementary concepts like “adaptation”. For instance, in a review on the differences and similarities between resilience and adaptability, Busch states, “while resilience tends to be in a response to some kind of adversity, stress, or pressure, adaptability does not necessarily involve any kind of negative situation” (n.d., para.8).

For the purpose of this study, the preferred understanding of resilience is that which is outlined in the multisystemic model of resilience (Hiebel et al., 2021). This definition accounts

for intra-individual source of resilience, interpersonal source of resilience, and socio-ecological sources of resilience (Hiebel et al., 2021, p.2). According to Wiig et al. (2020), “in this view, there is an emphasis on the individual’s, communities’, or organizations’ ability to regain equilibrium in circumstances of changes or to adapt to new norms, forms, and practices” (p.3). In the case of CRS in Canada and FGC-related care more broadly, there are several actors that have exhibited this adaptive capacity including survivors (micro), community-led organizations and healthcare providers (meso), and policy makers, hospitals, and universities (macro/exo) – all of which shape this complex system. Therefore, as Massari et al. argues in their study of complex systems approaches – resilience is thus a *property* of complex systems “which spontaneously emerges from the bottom as a result of both the actions of the system’s agents and their complex interactions” (p. 209). This emphasis on multifaceted adaptation is especially important given the recent introduction of this surgical procedure in Canada, which impacts survivors, the community-led organizations which offer FGC-related related supports, and the providers and clinics that specialize in this type of care. This next section will break down each level of resilience further in relation to this study’s demographics and then will conclude with a return to the application of a multi-system resilience lens.

### **Resilience and FGC (Intra-Individual/Micro Level Resilience)**

An important consideration when defining resilience is raised by Duit et al. (2010) who encourages resilience theorists working in social science spaces to consider the question “resilience of what, and for whom?” (p.265). This is a question I posed to myself in the process of identifying different instances of resilience amongst the various demographics explored in this study. For instance, Duit et al. (2010) argue, “notions of resilience as the ability to “bounce back”, “return to equilibrium” and to “reorganize after a disturbance” may have wholly different

meanings, depending on how the social system was configured to begin with and from whose viewpoint resilience is assessed” (p.365). Therefore, provided the different interpretations, meanings, and measurements of resilience, approaches *to* resilience that solely focus on an individual’s ability to “bounce back” can actually contribute to an increase in an individual’s sense of isolation – exacerbating their challenges in facing adversity (Auburn et al., 2020).

For survivors of FGC, resilience is often discussed within the context of psychological resilience (Glover et al., 2007; Conner et al.; 2021). In their study on the psychological and social challenges, Glover et al. (2007) highlight the emotional, physical, and identity impact FGC has for survivors (p.231). These challenges can be exacerbated particularly amongst FGC survivors who have immigrated to other countries and are encountered with health practitioners who are poorly adapted to meet their specific health needs (Jordal & Wahlberg, 2018). These exchanges with other actors across different systems (e.g., legal systems or health care systems) help to highlight the importance of a multisystem approach to resilience.

### **Resilience and Community-Led Organizations (Interpersonal/Meso Level Resilience)**

Non-profit organizations, particularly those which serve immigrant populations, often encounter instances of adversity (Carrillo, 2016). Such adversity frequently consists of limited funding, lack of governmental support or acknowledgement, constrained capacities (i.e., time and energy) of members, geographic challenges, and more (Carrillo, 2016). In Witmer and Mellinger’s study on organization resilience their focus is on non-profit organizations’ response to change. For Witmer and Mellinger, organizations that are resilient are those which have exhibited an adaptive capacity (2016, p. 255). As described in the section on situating resilience, adaptive capacity refers to the capacity of individual actors or groups and their ability to respond to adversity and create change (Craig et al, 2020, p.1758).

From data collected in their study, Witmer and Mellinger emphasized the connection between a strong commitment to the mission of the organization and the level of resiliency of that organization. Organizations that held a clear mission statement and were supported by members who shared in the beliefs and values of that organization, exhibited a high level of resilience. When a group of actors believe in an organization's mission – its purpose and its goals – it helps to bolster members' spirits and empowers them to respond *collectively* to challenges (Witmer and Mellinger, 2016). Members of FGC-related organizations are often compiled of survivors, human rights activists and advocates, researchers, care providers, educators, and more. These members are individuals who align themselves with the organization's mission and are passionate about raising awareness around FGC, eliminating FGC, protecting women and girls at risk of FGC, and offering supports to FGC survivors. Therefore, through their commitment to a shared cause, group members ultimately contribute to the organization's overall resilience (Witmer and Mellinger, 2016).

### **Resilience and Health Care (Socio-ecological/Macro Level Resilience)**

In Auburn et al.'s article, authors explore the social reality and resilience of health care professionals. Here Auburn et al. note that the conceptualization of resilience is often conceived at the individual level despite the connection to larger structural factors (2020, p.1). Behrens et al. (2022) describes the health care system as “a part of the critical infrastructure (on a local, regional, national, and even international level) ...making health care systems resilient is therefore of utmost societal importance” (p.468). This conceptualization of resilience helps to move beyond the micro-level (Auburn et al., 2020; Behrens et al., 2022; Ungar, 2020).

Acknowledging the resilience of health care systems within these broader contexts also helps to highlight health care systems' overall adaptive capacity to transform in order to meet the



changing needs of a population (Behrens et al., 2022, p.469). For instance, when we consider a substantial aging population, it requires some restructuring of health care system developments to ensure that the health demands of this population are met (Behrens et al., 2022). These demands may look like larger investments in home and hospital care for seniors or increases in specialist services like geriatricians, oncologists, or ophthalmologists (Royal College of Physicians and Surgeons of Canada). The same can be said for an increasingly *globalized* population in Canada – in order to continue to provide quality care, particularly within the context of FGC-related care, it becomes ever more important for the Canadian health care system to adapt as a means to provide cross-cultural health services, supports, and training.

### **Multisystemic Resilience**

Due to the complex and dynamic nature of resilience, it is common for researchers to sing its praises – recognizing its relevancy and vast applicability amongst a variety of disciplines at different interacting levels (Buikstra et al., 2010; Ungar, 2020). However, it is often for those same reasons that resilience as a theoretical concept is subject to criticism (Buikstra et al., 2010; Newsom & Myers-Bowman, 2017; Wiig et al., 2020; Shevell et al., 2021). When defining resilience for the purpose of this study, I discussed some of the challenges researchers faced, therefore, this section will focus on some of the main criticisms of resilience applications, offer some alternative ways of understanding resilience, and conclude the chapter with a return to the preferred understanding of resilience and its relevance for the purpose of this study.

One of the most common critiques of resilience is against its conceptualization as a personal characteristic or trait (Newsom & Myers-Bowman, 2017; Bogar Hulse-Killacky, 2006).

Arguments against this type of understanding are not only based on the implication that resilience is static but also that it puts the onus on the individual (Newsom & Myers-Bowman,

2017; Ungar, 2020). Such individualized approaches to resilience, which celebrate a person's ability to "cope", "bounce back", or "overcome", can actually cause more psychological harm, stress, and isolation (Auburn et al., 2020, p.2). Ungar (2020) explores this reductionist approach to resilience further in his examination of multidimensional approaches to resilience within the context of mental health. Here, according to Ungar (2020), when resilience is reduced in this way it "serves neoliberal agendas by blaming those who fail to thrive" (p.7)<sup>4</sup>. For instance, such perspectives fail to consider the differential access to resources that individuals might have access to in order to adapt. An approach to resilience which fails to account for the social, structural, and ecological determinants of resilience will only help to maintain social injustices (Ungar, 2020).

Similarly, in Ryan's article on everyday resilience as resistance, she seeks to further problematize this association between resilience and neoliberalism (2015, p.299). According to Ryan, "if we look for resilience "from below" as a tactic or strategy employed intuitively by populations, rather than something imposed from above, we can clearly see that not only is it much more prolific than the current literature implies, but that it can be a practice of resistance rather than simply a practice of coping" (2015, p.300). This alternative understanding of resilience also helps to counter arguments which situate resilience approaches in *opposition* to resistance approaches.

It is for that reason, as Shevell et al. (2021) states, "resilience must be seen as a "multidimensional construct", demanding a coordinated multisystem response" (p.2). A multisystem approach to understanding resilience successfully challenges the above criticisms

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<sup>4</sup> Neoliberalism is an economic and political philosophy that has faced criticism for contributing to several harmful socioeconomic consequences including "increased poverty, unemployment, and deterioration of income distribution" (Gatwiri et al., 2019, 90).

while simultaneously accounting for the complexity of these interconnected factors. This point is emphasized by Jaya et al. (2024), who in their article on the complexity of FGC within the Indonesian context, argues “by comprehending the complex factors, the actors involved can work towards promoting the health and well-being of girls and women” (p.7). This perspective is similarly shared by Jordal and Wahlberg (2018) in their examination of difficulties providing quality care for survivors. Here the adaptive capacity of actors is recognized not only at the individual level, but also at interpersonal and institutional levels as a means of coming together to overcome shared challenges. Therefore, a theoretical analysis like multisystemic resilience, that helps to illuminate the adaptive capacity of actors will help contribute to a more in-depth understanding of these complex systems and their connections to the successful introduction of CRS in Canada.

The combination of feminist intersectionality theory, complexity theory, and multisystemic resilience help to best conceptualize this complex research problem. As a study which seeks to explore the introduction of an elective genital procedure for survivors of FGC living in Canada, there are several components to this investigation which contribute to the study’s overall complexity at different levels. Firstly, the intersecting identities of this study’s main demographic are deeply entwined and affect their ability to access and receive quality care. By employing a theoretical perspective which accounts for these various forms of oppression, it allows for a more in-depth understanding of the study’s problem. Secondly, the inclusion of a complexity theoretical framework allows for a more complete picture of the CRS landscape in Canada and abroad – emphasizing the geographical, financial, and legal dimensions relevant to this study’s exploration. Lastly, by situating this project within a multisystemic resilience

perspective, it helps to highlight the adaptive capacity of key actors (i.e., survivors, healthcare providers, and FGC-related organizations) as they persevere despite the challenges that they face in navigating these complex systems and intersecting factors.

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

Outlining the study's theoretical frameworks is not only relevant to conceptualizing of the study's research problem but is also connected to the ways in which this study was undertaken. As such, it is important to outline how these theoretical perspectives inform the study's methodology and methods used. This research adopts a complementary methodological approach that blends qualitative data, including focus groups and qualitative surveys, to achieve a more in-depth understanding of the study's research problem. Additionally, this approach also draws from secondary sources including organizational webpages, reports, and community outreach initiatives, to further enrich the study's primary data and showcase how my understanding of CRS evolved throughout the research process. Lastly, thematic analysis is outlined as the chosen method of analysis for this study – well-suited to explore the complexity of investigations into the introduction of CRS in Canada.

### **Methodology**

#### ***Positionality Statement***

According to Landman (2006), “feminist methodology is specifically concerned with how, or whether, knowledge produced about social life can be connected with the social realities of women” (p.430). However, it is of great importance to emphasize that “women” is not a singular category (Landman, 2006). As previously discussed within the theoretical framework, women's social realities are influenced by several intersecting variables that impact their lived experiences and over the course of this study my interactions with participants and exchanges with community organizations and clinic team members was almost exclusively with women. Apart from one male physician, who took part in an information gathering event, every

physician, survivor, researcher, organization coordinator, and support worker I interacted with in relation to this study was a woman.

It therefore becomes important that I situate myself within the research when observing and interpreting the experiences of the women who shared their time and stories with me, who choose to participate in this project, and who supported the aims of the study. Particularly as Haraway (1988) argues, “there is no single feminist standpoint because our maps require too many dimensions for that metaphor to ground our vision” (p.590). For instance, as a woman, I can understand the feelings of discomfort and vulnerability in interactions with medical professionals (particularly male physicians) related to my sexual health, reproductive health, and concerns related to the functionality and appearance of my sexual anatomy. This sense of vulnerability is heightened through the level of trust we are forced to place in a medical professional – someone dealing with our health and the most intimate parts of our lives and our bodies. It can be an uncomfortable and overwhelming feeling to put your trust in someone and to believe they have your best interest in mind, the knowledge to *know* what is best, and the ability to competently *do* what is best if and when the time comes.

However, while I can empathize with that vulnerability, as a white woman born and raised in Canada, whose only interactions as a patient have taken place in the medical system within the culture in which I was raised, I can only imagine how these feelings of discomfort and vulnerability are amplified when you are navigating a healthcare system different to the one in which you were raised, may not speak the favoured language of that system, and have experienced a body-altering ritual of sociocultural significance that is often likely to be an unfamiliar practice to the providers responsible for your care and wellbeing. This matter of positionality is particularly relevant as it is in line with approaches to feminist-informed research

methodology, for which underpin this study. Here, by reflecting on the influences of my own identity, background, and experiences, I recognize my role as researcher, which according to Nencel (2014) in their study on situating reflexivity in feminist ethnographic texts, “comprises an essential component of this endeavor” (p.76).

A denounced misconception of feminist methodology had been that female researchers were better suited for emotionally laborious qualitative methods, such as interviews rather than numerical quantitative approaches, based on outdated beliefs that women were more compassionate than men and thus better listeners. This belief of qualitative research as “soft” has persisted within health and health science research where similar untruths and methodological prejudices continue despite evidence to suggest otherwise (Pope & Mays, 2020, p. 212). For instance, in their chapter on the quality in qualitative research, Pope and Mays highlight the often-complex nature of qualitative data and that the analysis of such data requires a high level of interpretative skill (Pope & Mays, 2020, p. 212).

Furthermore, Landman (2006) argues that there are in fact no research methods which are more distinctly feminist than others. Rather, it is through a feminist methodological perspective that researchers can help to improve upon current methods by way of emphasizing women’s social realities in their application – leading feminist methodologists to advocate for the usage of a diversity of methods in their research pursuits (Landman, 2006).

In a comparative piece on the subjective view of objectivity in research, Westmarland emphasizes the complementary nature between interviews and surveys arguing, “rather than the “us against them” relationship, interviews can give a deeper, more complex knowledge of the issues named by survey research” (Westmarland, 2001, p.9). Therefore, for the purpose of employing a complementary approach that would account for the diversity of women’s social

realities, I employed a methodological approach which included the observation and analysis of organizations involved in the support of survivors in Canada and abroad, the surveying of survivors in relation to their interest and experience related to CRS in Canada, and a focus group of Canadian physicians responsible for the referral and facilitation of CRS to take part in an open discussion format. The following section is an overview of the organizations I collaborated with and their involvement in the study's recruitment efforts, participant sampling, and data collection.

## **Methods**

In 2018, I completed a study that explored the experiences of Canadian physicians who provided reproductive health care to immigrant women in Canada with previous experience of some form of female genital cutting (FGC) (Leone, 2018). This study consisted of qualitative interviews with Canadian obstetricians and gynaecologists (OB-GYNs), family physicians, and registered nurse practitioners across Ontario and Québec (Leone, 2018). Each research participant graciously shared with me their time and expertise – providing invaluable insight into the care of survivors in Canada.

My fieldwork for this study took place between 2016-2017, during which information on FGC-related care *specific* to the Canadian context was exceptionally limited. There were, however, some exceptions which included interested healthcare providers, researchers, and activists and advocates working to raise awareness of FGC as a Canadian issue. Due to the efforts of passionate individuals who acknowledged the importance of addressing the topic of FGC in Canada, Canada received the brief clinical guidelines document offered by the Society of Obstetricians and Gynaecologists of Canada (SOGC), statements shared by human rights organizations such as the Ontario Human Rights Commission, independent FGC-specific



healthcare modules in development by some university medical programs, and a few clinics that specified “female genital mutilation/cutting” in their clinic services and specialization.

Through these small-scale changes, awareness about FGC as a Canadian issue began to expand as a result, particularly with the foundation of the End FGM Network Canada in 2018. The End FGM Network is an organization that seeks to bring an end to FGM globally by way of education and awareness. Other End FGM Networks include End FGM European Network and the End FGM/C U.S. Network. Having our own faction of the End FGM Network helped to bolster arguments that FGC was in fact a Canadian issue – one deserving of public attention and governmental action in order to help protect Canadian women and girls at risk of FGC as well as to support survivors living within our nation’s borders. The momentum sparked by the End FGM Canada network helped to expand these awareness-raising efforts with an emphasis on collaboration and community outreach whereby the End FGM Canada Network helped to spread its message not only through amplifying the voices of Canadian survivors, but also by bringing together individuals who were specialists in their respective fields and held frontline positions working in and alongside survivor communities.

Accordingly, by the time I began research preparations for this study in 2022, it was important to reach out to organizations like the End FGM Canada Network and I did so in the role of volunteer – volunteering my time, knowledge, and research and writing skills. The purpose of volunteering was fourfold: to build rapport with FGC-related organizations, to gain further insights into FGC research within the Canadian context, help contribute to the organization’s initiatives to support survivors living in Canada and abroad, and to engage with likeminded individuals who are passionate about improving the lives of survivors living in Canada. As part of this volunteer work, I was also able to establish professional relationships

with various network coordinators to help in the distribution of my study as well as support my participant recruitment efforts.

During this period as a volunteer, I would take notes, join meetings with other volunteers and members, and attend conferences and speaking series. My involvement with these organizations offered a pathway into the communities that provide support to survivors in Canada and abroad – while also offering further insights into the needs and experiences of survivors, clinicians, and other front-line workers by way of indirect, secondary data through their organizational webpages, reports, initiatives, workshops, and more. In a paper on the importance of secondary research, Thin (2013) argues that by engaging with secondary sources, the researcher demonstrates how they are “drawing inspiration and information from a rich variety of other knowledge sources” (p.42), sources which ultimately help to complement and support the study’s primary modes of data collection. Therefore, offering an overview of secondary sources is not only important to help illustrate what they offer directly, but also, as Thin describes, “more indirectly for what they reveal about the cultural processes and institutions they are associated with” (p.42). In this next section I will describe each of the FGC-related organizations and clinics, their connection to the goals of the study, and how they helped to contribute to the primary data collection process. By doing so, the following section helps to illustrate how my research evolved through interactions and exchanges with what Thin (2013) describes as “knowledge producers” – organization directors and volunteers, clinicians, activists, researchers, casual acquaintances – and engagement with the work they produce in relation to CRS and FGC more broadly (p. 41).

## **FGC-Related Organizations**

I engaged with different FGC-related organizations and clinics in Canada and abroad in order to develop a deeper understanding of the needs of survivors, service providers, advocates, and other types of frontline workers with regards to CRS and FGC-related care more broadly. By engaging with these various organizations and clinics they became instrumental not only in terms of the insights that they provided, but also in terms of supporting the study goals – often both in terms of simply believing in the aims and importance of the project as well as helping to disseminate recruitment materials. These organizations included the End FGM Canada Network, Women’s Health in Women’s Hands, Sahiyo: United Against Female Genital Cutting, Restore FGM, and Tadwein Centre for Gender Studies. Each of these organizations and clinics have established initiatives to improve the quality of care and support that survivors receive in Canada and abroad through collaborative efforts between survivors, human rights activist, healthcare professionals, researchers, social workers, educators, and writers.

### ***The End FGM Canada Network***

The End FGM Canada Network is an organization that seeks to bring an end to FGC by way of education, awareness, and prevention efforts. In addition to increasing the number of supports available for FGC survivors, the organization also engages with professionals to offer trauma-informed culturally sensitive training and tools. Sessions developed for healthcare professionals are intended to improve providers’ understanding and competency around FGC-related care in order to prevent instances of discrimination and stigmatization that many survivors face in their healthcare encounters.

My volunteer experience with the End FGM Canada Network began in the fall of 2021. I reached out to express my interest in the organization’s purpose and initiatives and to inquire

about volunteer opportunities. During this period, the End FGM Canada Network was in the process of launching several different projects including their Joining Hands Project and Miss Klitty. Funded by the Canadian Department of Women and Gender Equality Canada (WAGE), The Joining Hands Project was created to help develop systems of support for women and girls living in Canada that may be at risk of FGM/C as well as survivors. The Joining Hands Project takes a culturally sensitive and trauma-informed approach in their online training modules, which were developed for Canadian professional who work in FGM/C-impacted fields such as medicine, mental health, education, social work, and law enforcement (End FGM Canada Network).

The End FGM Canada Network's Miss Klitty Project was developed to help normalize discussions around the female body – particularly in terms of female sexual anatomy. By normalizing discussions around female sexual anatomy, it was the organization's intent to help remove the shame and stigma that is often associated with female genitalia. To accomplish this, the End FGM Canada Network's Digital Communications Officer created a cartoon depiction of an anatomically correct clitoris. The clitoris cartoon, Miss Klitty, would be depicted as cute, colourful, and confident. My involvement in this project took place in the very early stages where I would meet virtually with the organization's directors, digital communications officer, and other volunteers to discuss how best to launch the organization's new global goodwill ambassador. In order to share Miss Klitty's message far and wide, two methods of creative distribution were developed. Firstly, one could make their own Miss Klitty by following the End FGM Canada Network's sewing pattern with instructions. The purpose of this sewing pattern was not only to create a fun and interactive way to share Miss Klitty's important message, but also to give individuals the opportunity to create their own unique Miss Klitty that best

represented their personality. Secondly, individuals were also encouraged to colour their own Miss Klitty with the help of the End FGM Canada Network's colouring pages. The Miss Klitty colouring pages depicted a smiling Miss Klitty topped with a crown and a heart illustration situated in the centre of cartoon ambassador's chest. Surrounding Miss Klitty was positive messaging such as "*born perfect*", "*I am unique*", and "*protect me*" printed between smaller depictions of anatomically correct clitorises. The colouring pages offered another creative outlet to help celebrate and appreciate one's own clitoris. To help distribute Miss Klitty's message further, each of these interactive materials were tagged with the End FGM Canada Network's social media accounts and relevant hashtags so users could share and post their own Miss Klitty creations.

During this period as a volunteer for the End FGM Canada Network, I was also asked to participate in their annual conference in recognition of the International Day of Zero Tolerance for Female Genital Mutilation on February 6<sup>th</sup>. This conference was the organization's first ever two-day conference which was held virtually on both February 6<sup>th</sup> and 7<sup>th</sup> 2024. My participation in this conference was two-fold – I was asked to both moderate a panel and participate as a research panelist in their Research Panel titled, "*Exploring FGM/C Research in Canada and Abroad*". This allowed me the opportunity to not only share about my own research, preliminary findings, and participant recruitment materials, but also gave me the chance to connect with other researchers in the field of FGC-research and engage in meaningful discussions regarding the future of FGC research in Canada and abroad.

In terms of participating in the study's recruitment efforts, the End FGM Canada Network helped to circulate recruitment materials via their organization's email list serve, Instagram page, and quarterly newsletter. Additionally, the organization's director helped to

connect me with survivors that were able to review the study's online survey prior to dissemination.

***Sahiyo: United Against Female Genital Cutting***

Sahiyo: United Against Female Genital Cutting (Sahiyo) advocates for the rights of girls and women against the continuation of FGC and is one of the largest FGC-related non-governmental organizations in the United States. Established in 2015, Sahiyo's initial focus was on the Dawoodi Bohra community in India, but the organization has since branched out to not only include other Asian communities that are affected by FGC, but also other FGC-affected communities more globally. Sahiyo employs a committed team of activists, advocates, researchers, writers, and more – all of whom contribute their expertise towards supporting the organization's various programs, educational campaigns, community outreach initiatives, and international FGC research projects.

I began volunteering with Sahiyo in February 2023. During this period, I connected with the organization's Communications Coordinator and Research Coordinator. After several meetings to finalize our shared memorandum of understanding it was decided that I would write blogs for Sahiyo in exchange for the organization to help distribute the study's recruitment materials. Sahiyo's Blog Platform helps to highlight survivors' FGC stories, FGC-related news articles, FGC-research projects, and more. During this period, I published four blogs with Sahiyo, which included: *'Exploring Canadian Physician's Experiences Providing FGC-Related Care'*, *'Psychosexual Care for FGM/C Survivors: An Interview with Dr. Reham Awwad'*, *'FGM/C Sexual Education and Prevention: An Interview with Dr. Reham Awwad'*, and *'The African Women's Clinic: An Interview with Australia's Only FGM/C Clinic'*.

In terms of participating in the study's recruitment efforts, Sahiyo was instrumental in circulating the study's recruitment materials via the organization's members email list serve, social media pages (Facebook and Instagram), blog postings, and monthly newsletter.

### ***Women's Health in Women's Hands***

Women's Health in Women's Hands (WHIWH) is a Toronto-based Community Health Centre that specializes in the care of racialized women. WHIWH's excellent team of physicians, nurses, counsellors, community outreach workers, and more have contributed to the centre's reputation as a safe and accessible space for racialized women to receive quality care. WHIWH offers a wide range of health services, such as pre and postnatal care programs, mental health support and counselling, HIV-AIDS prevention education, and female genital mutilation/cutting (FGM/C) projects like Flourish.

Launching as a collaborative community-based project to support survivors, Flourish was established in 2018 as the product of nearly 25 years of WHIWH's advocacy work in FGM/C. According to the Flourish webpage, "using arts-based workshops and advocacy initiatives, Flourish engaged survivors, promoted a framework for compassionate service delivery, and improved dignified and appropriate healthcare" (Flourish Communities Collaborating to Address FGM). To help improve the access and delivery of services for survivors in Canada, Flourish developed an online access map to help connect survivors to safe and reliable services. The map allows users to filter by province, service, and/or type of violence experienced (e.g., female genital mutilation/cutting, domestic violence, sexual violence, human trafficking, etc.). For instance, survivors looking to find clinics that offer clitoral restoration surgery can simply select the "Reconstructive Surgery" option and can filter their selections – directing them to two specialized Canadian clinics: Sensolia and Lotus Obstetrics and Gynecology.

I first contacted WHIWH in February 2023 after learning more about the clinic's Flourish project during a presentation by the project's coordinator in the End FGM Canada Network's annual conference on February 6<sup>th</sup>, 2023, for the International Day of Zero Tolerance of Female Genital Mutilation. After meeting with the project's coordinator to learn more about the project and share about my study, it was decided that in exchange for distributing the study's recruitment materials that I would share any relevant insights from my Physician's Forum with the project coordinator that may prove helpful in the development of their Access Map. WHIWH helped to circulate the study's recruitment materials via their social media accounts (i.e., Instagram) and through their email listserv.

### ***Restore FGM***

I first reached out to Restore in February 2023 after coming across an Aljazeera article published on March 25, 2022, titled, ‘*Starting Over*’: *FGM Clinic gives hope to traumatised Egyptians*. After several unsuccessful attempts of connecting with other Canadian healthcare clinics and professionals, FGC researchers, and FGC-related organizations, I began to expand my search for experts in the field of FGC restorative procedures more globally – particularly those who were taking a uniquely multidisciplinary approach to FGC-related care. My thought in doing so was that I would not only be able to engage with more experts in this field, but that I could also learn what was working successfully internationally – particularly in countries with higher prevalence rates – that may be helpful to implement here in Canada given the procedure's more recent introduction in Canadian healthcare services.

Restore FGM is Egypt's first multidisciplinary clinic for FGC survivors located in the bustling city of Cairo. Still today, Egypt maintains some of the highest rates of FGC amongst other high prevalence-rate countries on the globe with a rate of 87.2% for women and girls aged



between 15 and 49 (FGM/C Research Initiative). According to FGM/C Research Initiative, an initiative hosted by Orchid Project, “with a population of nearly 95 million, Egypt has the greatest number of women and girls who have experienced FGM/C of any country in the world”. To further add to these numbers, Egypt has also experienced an influx of refugees in recent years from countries with similarly high rates of prevalence. For example, since April 2023, Egypt has received nearly 450,000 Sudanese refugees escaping conflict, many of whom are women and girls who have either undergone FGC or are at risk.

In terms of FGC, Sudan shares similar prevalence rates to Egypt with approximately 86.6% of women and girls experiencing FGC (FGM/C Research Initiative). However, the *type* of cutting differs from that which is found in Sudan where infibulation is the “type” of cutting most commonly practiced compared to Egypt where the preferred methods of cutting fall under the WHO’s categorization of “Type I” and “Type II”. Although the types of cutting are different, the preferred agents of cutting are largely similar. For example, Egypt is the most medicalized country in the world when it comes to performing FGC with 78.4% of incidences being carried out by healthcare professionals (FGM/C Research Initiative). Cutters in Sudan are similar to Egypt in that approximately  $\frac{3}{4}$  of incidences are performed by either nurses, midwives, or other types of medical professionals (FGM/C Research Initiative). Information about Egypt’s prevalence rates and contributing factors to their rise in numbers are important because they help to offer insights into the specific needs of survivors visiting Restore and accessing their services.

Since the initial outreach period in 2023, Dr. Awwad and I kept in touch – sharing updates if and when relevant. For instance, I interviewed Dr. Awwad for two of my blog postings for Sahiyo to help raise awareness about their work across North American audiences. Eventually I was able to meet Dr. Awwad in person by flying to Cairo, Egypt the following year

in February 2024 to visit Restore in-person. When I arrived at the clinic I was greeted by Dr. Awwad, Dr. Seifeldin, and a visiting medical student from the United States – all of whom had just arrived back in Cairo the night before following a conference in Geneva moderated by Dr. Seifeldin. The team's energy was palpable – feeling rejuvenated in their efforts to expand clinic operations, initiate new projects, and publish ongoing works that could revolutionize FGC-related care and offer non-invasive alternatives to CRS.

Co-founded by aesthetic and reconstructive surgeon Dr. Reham Awwad, and urogynecologist and aesthetic gynecologist, Dr. Amr Seifeldin, Restore opened their doors in June 2020 – offering a patient-centered approach to health care, where every FGC survivor's treatment plan was uniquely tailored to meet their individual needs. Clinicians at Restore offer several different treatment options to patients, but what makes Restore multifaceted is their emphasis on non-surgical interventions and helping survivors by prioritizing their psychosexual health and sexual education first and foremost.

Restore offers survivors a number of different surgical and non-surgical treatment options, ranging from clitoral reconstructive surgery to regenerative and functional gynecology to platelet rich plasma (PRP) injections into specific sites of the genitalia. As pioneers in this field, Dr. Awwad and Dr. Seifeldin were invaluable in terms of helping me to achieve a deeper understanding of the challenges and triumphs of running a multidisciplinary FGC-clinic – especially one that opened in the height of the COVID-19 pandemic. Through our meetings and our conversations, I became increasingly aware of some of the difficulties physicians encounter when it comes to offering this type of specialized care. Despite their ground-breaking work and an overwhelming desire for the services they provided, clinicians continued to encounter financial and administrative barriers that mirrored those experienced by Canadian practitioners.

### ***Tadwein Center for Gender Studies (Tadwein)***

I first learned of Tadwein during one of my meetings with Dr. Awwad where she had shared about their recent collaboration to help develop an FGC-prevention campaign with messaging targeted towards men. Tadwein was first established in 2014 with the goal of promoting gender equality in Egypt. Since its foundation, Tadwein has consistently produced some of the best research in Egypt around gender-based violence interventions. Tadwein has developed several different campaigns including: ‘*Don’t Touch Me*’ – a campaign addressing incidents of child sexual abuse, ‘*I Have my Period*’ – a campaign in recognition of World Menstrual Hygiene Day, ‘*My Pain is Real*’ – a campaign to support women in Egypt and abroad who have experienced medical discrimination, ‘*Slayed By Harassment*’ – a campaign that calls attention to the high rates of sexual harassment that women in Egypt experience, and ‘*Her Body is not Yours*’ – a campaign held during the 16 Days of Activism Against Gender-Based Violence (GBV) to combat gender-based violence worldwide.

In terms of FGC-related campaigns, Tadwein has created the ‘*She is Intact*’ Campaign and ‘*Endless Pain*’ Campaign, both of which are in acknowledgment of June 14<sup>th</sup> – Egypt’s national day for the elimination of female genital mutilation along with ‘*Stop the Medicalization of FGM*’ to denounce the harm caused by medical professionals who participate in cutting and “*Say No To FGM*” Campaign for the International Day of Zero Tolerance for FGM.

When speaking about their FGC-related campaigns, Tadwein employee, Layla<sup>5</sup>, emphasized the importance of a unified message. In order to achieve this unified message, it is crucial that there is no religious or medical content. The medical aspect was of special interest given the fact that the majority Western FGC-related organizations and clinicians *rely* on

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<sup>5</sup> A pseudonym was assigned to protect the employee’s privacy.

emphasizing the medical health complications associated with different forms of cutting to encourage practitioners to abandon the practice. However, by emphasizing these health complications, associates of Tadwein have instead found that rather than influencing women to reject FGC practices, it (unintentionally) encourages women to make a *shift* in the “type” of cutting they perform. Layla offered an example of this shift with the recent influx of Sudanese women who most commonly practice infibulation – here Layla noted that when women were made aware of the associated health complications of infibulation upon arrival in Egypt, that they would shift to a form of cutting that emphasized *fewer* health complications, such as the WHO’s categorization of Type 1 or Type 2 instead of abandoning the practice altogether.

Tadwein works hard to tackle issues impacting women and girls in Egypt, such as femicide, child marriage, and FGC and tried to highlight how such issues are often linked – increasing during times of conflict where decreases in security, education, and economic prosperity lead to higher rates of gender-based violence. Like most FGC-related organizations, Tadwein is reliant on outside funding and receives most of their financial support from international organizations and governmental bodies that promote gender equality. Therefore, when it comes time to “package” their various programs it is common for Tadwein to organize them together. By doing so, it is not only cost effective for them as a non-for-profit organization, but also helps to highlight the interconnectedness of femicide, child marriage, and FGC under the overarching theme of gender-based violence (GBV).

Discussions with Egyptian healthcare providers and FGC-related organization employees offered a turning point in the way I conceived my research problem. The challenges highlighted by these groups provided invaluable comparative insights around access to FGC-related supports and services for survivors, roadblocks in financing FGC-related care, and difficulties in sourcing

support for community-led projects and initiatives – each of which were observed in Canada. Therefore, by looking *outside* of Canada it helped me to better understand what was happening *within* it – allowing for a more well-rounded perspective of the complex factors that impact Canadian physicians and survivors in the Canadian diaspora when it comes to CRS and FGC-related care more broadly.

This review of several FGC-related organizations and clinics, helped not only identify how the recruitment materials for the study’s primary data collection methods were distributed and circulated, but also offered insights which further highlight the complexity of the study’s research problem – emphasizing a “close dependence” of several key factors (de Figueiredo, 2018, p. 16). The focus on this complex interconnectedness, is similarly linked to discussions on primary modes of data collection, which as Thin (2014) describes, “must always be inspired and informed by what we have learned from *other* sources” (p.39). Therefore, by outlining what was learned from FGC-related organizations and clinics – largely through their webpages, reports, initiatives, and workshops – these secondary sources help to inform the following section, which focuses on participant sampling and primary data collection. This section is broken down by demographic – outlining the target population, expanding on recruitment efforts, and methods of data collection for each group.

## **Participant Sampling and Primary Data Collection**

### ***Survivor Demographic and Survey Component***

As a recent reparative option for survivors in Canada, it was important for me to develop a deeper understanding as to why survivors in Canada were interested in CRS, what they hoped

to achieve by having the surgery, and what their post-surgical outcomes were (if they had undergone CRS) given the limited data available particularly within the Canadian context.

An **online survey** was chosen as the desired method of data collection for this demographic to reach as many survivors as possible who would be interested in sharing their experiences and opinions around CRS – especially those who had no desire for a sit-down interview – whether due to personal time constraints or a lack of comfortability around sharing their thoughts in-person.

According to Creswell and Poth (2016), “online data collection helps create a nonthreatening and comfortable environment and provides greater ease for participants discussing sensitive issues” (p.159). Braun et al. (2021) highlight this quality of “*felt* anonymity” within online surveys that can increase perspective participants sense of comfortability (p.7). Here “*felt*” is emphasized because, technologically speaking, factors like IP addresses may prevent online surveys from being classified as *entirely* anonymous (Braun et al. 2021). Despite not being *entirely* anonymous, that does not prevent online survey users from *feeling* completely anonymous – a feeling which can encourage participants to be more open in what they choose to share (Braun et al. 2021). Due to the personal nature of CRS and FGC more broadly, it was important to me to offer a secure and accessible method of participation that would offer participants that sense of anonymity.

In order to further expand the pool of qualifying participants, the categories for survey participants were diversified to include survivors who had undergone CRS (with no limit on the amount of time that had passed since the surgery was performed); survivors who, after counselling, decided not to move forward with CRS; survivors who were denied CRS; and survivors who were in the early stages of deciding whether or not to undergo CRS. Therefore,

employing a survey helped to improve participant accessibility to participate in the study while also reaching a greater number of potential participants.

An **initial skeleton survey** (see Appendix A) was developed, which included demographic questions (e.g., current age, sociocultural background, age, and location of cutting, and country of origin); ranking questions to identify motivations for undergoing CRS (e.g., pain relief, sex-life enhancement, and body image); and a combination of matrix and open-ended questions to determine survivors' experiences and postoperative outcomes (e.g., what were the postoperative functional outcomes, did the surgery meet expectations, in what ways have their lives improved following CRS, and how have their views on CRS changed since migrating to Canada).

In Braun et al.'s article on online surveys as qualitative research tools, they emphasize the role and relevancy of open-ended questions in online surveys. Braun et al. (2021) argue, "that qualitative survey datasets *can* provide richness and depth, when viewed in their entirety, even if individual responses might themselves be brief" (p.3). As noted above, the use of online surveys not only provides a level of flexibility, accessibility, and felt anonymity, but also, with the inclusion of open-ended questions, can help to capture the personal experiences and views of participants, which is well aligned with my feminist methodological approach.

A meeting to review the skeleton survey was organized with a survivor to incorporate the insights, suggestions, and recommendations from FGC community members in order to ensure that the survey questions were reflective of the realities and concerns of participants. This collaborative construction of the qualitative survey component aligned with the feminist informed research methodologies which underpin this study's methods section. By including

participant community members in the research design phase this helped to ensure that the voices of survivors were at the centre of this research process (Liu, 2025). The compensation for this meeting was \$50. The review took place over Zoom, where the community member reviewer and I met to go over the survey skeleton for feedback, recommendations, and suggested edits. The community member was instrumental in providing valuable insights to help improve the proposed questions. The review was focused on inclusive terminology, accessible language, and improving the overall flow and clarity of the online survey. Following this discussion, I incorporated the feedback received and made the recommended changes to the survey skeleton. Once the changes were made, I sent the survey back to the community member reviewer for any final edits where we confirmed that the survey was ready for dissemination. The survey questions were then organized into SurveyMonkey and the associated survey link and QR code were inserted into the online survey recruitment materials.

The aims identified in the survey recruitment materials were as follows: to develop a greater understanding of survivor's interests, motivations, and/or expectations in electing to undergo CRS, to identify how well a survivor's surgical outcomes meet their initial expectations, to improve the referral process for survivors who wish to undergo CRS, and to highlight the importance of quality care for survivors in Canada. **Survey recruitment materials included posters, PDFs, and images. These materials were shared via email, blog postings, organization newsletters, social networking forums, and Instagram story and grid posts** (see Appendices B-G). Organizations such as the End FGM Canada Network, Sahiyo: United Against Female Genital Mutilation, and Women's Health in Women's Hands were instrumental in the sharing of recruitment materials. In addition to these methods of dissemination,



recruitment materials were also shared with participating physicians, advertised during conference participations, and linked in forum-based social networking sites like Reddit.

Six survivors completed the online qualitative survey. With this emphasis on survivors, this method of data collection aligned with my feminist-informed research methodology, as it employed an individual-centered approach whereby the experiences and voices of participants were prioritized (Winfield, 2024). Of the six survivors who completed the online qualitative survey, two had undergone CRS, three were interested in undergoing CRS, and one was not interested in undergoing CRS. Pseudonyms have been assigned to each of the online qualitative survey participants. Below is a description of each of the survey participants.

### ***Dela***

Dela is between the ages of 25 and 34, married, and has completed some graduate-level education. Of the different types of FGC, Dela stated that Type 2 (the partial or total removal of the clitoral glans and labia minora – with or without the labia majora) most accurately aligned with the type of cutting she experienced. In terms of CRS, Dela first heard about the surgical procedure from her obstetrician and gynecologist (OBGYN). Despite learning about the procedure and expressing interest in it, Dela has yet to undergo CRS or do any further research into the procedure. However, according to Dela, her interest in CRS stems from her desire to “get their clitoris back as it was removed”.

### ***Nadine***

Nadine is between the ages of 25 and 34, married, and has completed college/university. Of the different types of FGC, Nadine stated that Type 2 (the partial or total removal of the clitoral glans and labia minora – with or without the labia majora) most accurately aligned with

the type of cutting she experienced. Nadine is one of two survey participants to undergo CRS. For Nadine, the decision to undergo CRS took 1-2 years to make.

### ***Chelsea***

Chelsea is between the ages of 25 and 34, single, and never married. Chelsea was born in Toronto and has completed college/university. Of the different types of cutting, Chelsea most accurately aligns with Type 1 (the partial or total removal of the clitoral glans and/or the prepuce/clitoral hood). When it comes to CRS, Chelsea first heard about it online; however, she is not interested in undergoing the procedure. When asked why she was not interested in CRS, Chelsea stated that it was due to fact that “only the clitoral hood was removed” and she has not personally experienced any impacts that would warrant surgery.

### ***Marie***

Marie was born in Somalia and is between the ages of 19 and 24. Marie is single – never-married and has completed some college/university. Of the different types of cutting, Marie most accurately aligns with Type 2 (the partial or total removal of the clitoral glans and labia minora – with or without the labia majora). Marie first learned about CRS through the social media app TikTok. Marie has not yet undergone CRS but has expressed interest doing so. When looking for more information about CRS, Marie has relied on other peoples’ experiences in addition to online sources like Google and YouTube. Marie’s interest in CRS stems from her negative experiences in undergoing FGC, which according to Marie, left her feeling mutilated, lied to, and incomplete.

### ***Lauren***

Lauren is between the ages of 35 and 44, single/never-married, and has completed graduate-level education. In terms of cutting, Lauren most accurately identifies with Type 1 (the

partial or total removal of the clitoral glans and/or the prepuce/clitoral hood). Lauren expressed an interest in undergoing CRS. This interest stems from Lauren's desire for improved sensitivity as she stated she currently has none. When Lauren first started looking for information about CRS, she would look online on Reddit.

### ***Aisha***

Aisha was born in Somalia and is between the ages 35-44 years old. Aisha is married and has completed college/university. Of the different types of FGC, Aisha's experience most accurately aligns with Type 3 (infibulation – the narrowing of the vaginal opening through the creation of a covering seal. Formed by the cutting and repositioning of the labia minora, labia majora, and removal of the clitoral prepuce/clitoral hood and glans). Aisha is the second participant to undergo CRS – a decision which took her over 5 years to make. Aisha expressed that her experience of living with FGC had not been good, which influenced her decision to undergo CRS along with the fact that she felt that all her glans had been removed. Aisha was also interested in CRS to help alleviate pain she was experiencing from complications of her cutting and for increased clitoral stimulation. In terms of which areas Aisha experienced the most improvement, Aisha noted pain relief and body image. Overall, Aisha was satisfied with the referral process and the level of support she received following surgery; however, when it came to the surgery itself, Aisha was left dissatisfied with the recovery process and her post operative outcomes.

### ***Physician Demographic and Data Collection***

Through my previous study on the reproductive healthcare of immigrant women living in Canada who had previously experienced FGC, I had established working relationships with

various healthcare providers who had exhibited an expertise in FGC-related care. Although these providers were familiar with the specificities of FGC-related care, only one of those previous informants was trained in the surgical procedure for which this study intended to explore. As a result, I began online searches for physicians who had been referenced in relation to CRS in Canada. Due to the recent introduction of this surgical technique in Canada there were very few names to appear in the search – limiting the scope of potential healthcare participants.

Purposeful sampling technique was used in identifying participants to take part in the Physicians' Forum focus group. Participants were identified via online searches and selected based on their skills and expertise in the realm of FGC-related care – particularly in terms of their knowledge of restorative procedures. Participants were contacted via their public email addresses and/or professional website contact information and asked to take part in the Physicians' Forum focus group discussion following an information gathering phone call. I remained in contact with physicians throughout the data collection phase – keeping in touch and slowly building a rapport over several months.

In December 2023, after securing a date and time suitable for all participants, I held the Physician's Forum focus group discussion with 3 practicing physicians. Each participant had professional experience providing FGC-related care in Canada and was trained in restorative surgical techniques. The selection of participants offered a broad representation of FGC-related care insights nation-wide with physicians based in Alberta, Ontario, and Québec. In line with the Research Ethics Board (REB) protocols and recommendations, physicians were required to provide their consent in advance of participating in this study's focus group discussion. Physicians who consented in the study were offered a series of options in terms of identification in the study's write up, which included the option for participants to choose their own

pseudonym, have a pseudonym assigned, or choose their own name. Participants identified their preferences over a year after their initial focus group participation, which emphasized the evolving nature of researcher-participant relationships and the importance of on-going consent. According to Winfield (2024), this matter of on-going consent is foundational to strategies for feminist and equity-oriented research. Here, each participant in this study made their choice freely and independently and the document both reflects and respects their individual preferences.

### ***Dr. Cathy Flood***

Dr. Flood is a Urogynecologist at the Lois Hole Hospital for Women at the Royal Alexandra Hospital as well as a Professor in the Department of Obstetrics and Gynecology, Faculty of Medicine and Dentistry at the University of Alberta in Edmonton, Alberta. Dr. Flood has practiced medicine for over 30 years and has encountered many patients with FGC throughout her medical career. Due to her experience providing care to FGC survivors, Dr. Flood began teaching her medical students about FGC and has been doing so for quite some time.

Dr. Flood does not have an FGC-specific clinic in Edmonton, Alberta; however, as a surgeon with a special interest in FGC-related care, she was trained in clitoral restoration under Dr. Marci Bowers from California, USA. Despite performing CRS on several occasions, Dr. Flood has since discontinued this surgical procedure as she does not believe the literature fully supports the surgery's claims at this time. Although Dr. Flood no longer performs CRS, she remains open to referring survivors who are interested in undergoing CRS to clinicians in other provinces.

### ***Dr. Angela Deane***

Dr. Deane is an obstetrician and gynecologist based out of Toronto, Ontario. Dr. Deane first learned about FGC during her time as a labour and delivery nurse. Since receiving her medical degree, Dr. Deane's interest in FGC-related care has continued and she has worked to improve the healthcare experiences of survivors by way of education and implementing a multidisciplinary approach to her practice.

In terms of CRS, Dr. Deane traveled to San Francisco, California to learn the clitoral restoration surgical technique under Dr. Marci Bowers and joined two larger surgical missions with Dr. Bowers to Kenya. Dr. Deane opened a clinic in Ontario where she offers care to survivors. Currently, the clinic team is comprised of Dr. Deane and three of her colleagues who are all Obstetricians and Gynecologists with the hopes of one day having a psychologist. On average Dr. Deane sees two patients a week who have been affected by FGC.

### ***Dr. E***

Dr. E is a Gynecologist who specializes in Gynecologic Surgery and Aesthetic Medicine in Québec. Dr. E's clinic offers a variety of treatments including face and body, gynecological, and aesthetic treatments. What sets Dr. E's clinic apart from other women's health or gynecology clinics, is direct mention of FGC. When it comes to sexual health and wellness, Dr. E's clinic highlights that, "with great care and discretion, we will work with you to alleviate any social, psychological, and physical pain you may be suffering from associated due to sexual dysfunctions". Included in this list of sexual dysfunctions is female genital mutilation/cutting. Additionally, under Dr. E's gynecological surgery offerings, vulvar aesthetic surgery is identified as a potential corrective surgery for patients who may have experienced congenital malformations after undergoing FGC.

Dr. E first became interested in the topic of FGC in 2000 after she was contacted by a team in Geneva and Brussels who were conducting a study on the sexual functioning of FGC survivors. From a surgical perspective, Dr. E worked with reconstructive surgery of the vulva for several malformation types during her pediatric and adolescent gynecology fellowship.

The Physicians' Forum focus group discussion was approximately 1-hour long and took place over Zoom via a recorded video call to account for the geographic distance between providers. During the Physicians' Forum, **semi-structured questions were asked to generate discussion** (see Appendix H). Physician participants were encouraged to speak freely and openly in a casual online setting. In Tritter and Landstad's (2020) chapter on focus groups and their application as a qualitative method of data collection within health science research, they describe focus groups as, "a type of group interview but one in which the primary aim is to promote interaction between the group members rather than to have each participant answer every question" (p.58). This was precisely my aim in conducting a focus group with care providers – to encourage open dialogue and communication between experts in the field. Moreover, as the claims of the surgical outcomes from CRS continue to be debated amongst healthcare professionals, a focus group approach would foster a space for different views and opinions to be discussed in real time. Here my role was more so that of a moderator where I helped to facilitate the discussion – learning more about their experiences providing FGC-related care in Canada and identifying their process of decision-making in terms of referring survivors for CRS. Therefore, this method of discussion, whereby participants were required to interact with one another, was especially useful in terms of generating a more in-depth understanding of key topics.

The use of this qualitative data collection method was also in line with my feminist informed research methodology and intersectional feminist informed theoretical framework. Firstly, as a method of data collection, focus group formats help to empower participants to share their own experiences and perspectives – prioritizing participant voices (Leavy, 2007; Spadacio et al., 2024). According to Leavy (2007), this method of qualitative data collection “offers the opportunity for conversation to move beyond generalized and public meanings to encourage more intimate and private expressions” (p.149). By uplifting participant voices, this method aligned with feminist informed research methodologies which seek to prioritize participant voices. Additionally, a focus group format was also consistent with the collaborative nature of feminist informed research methodology. For instance, according to Leavy (2007), “collaboration exists on a continuum...there are various degrees and ways in which that collaboration can occur” (p.169). Therefore, in terms of this open discussion forum setting, it enabled participants to lead the discussion – thus accounting for a more collaborative role in the production of knowledge.

The 1-hour long video recording of the Physicians’ Forum focus group discussion was manually transcribed. Supplementary data collected by way of notes recorded during the focus group were also typed and included alongside the detailed discussion transcription.

## **Data Analysis**

The chosen method of analysis for data collected was thematic analysis. Thematic analysis is especially relevant to this study’s aims as it focuses on identifying, analyzing, and reporting themes or patterns within qualitative data, but what makes it most applicable is that it moves beyond just counting words and towards a more dynamic search for underlying meanings



and insights (Xu & Zammit, 2020). This description of the interpretative nature of thematic analysis highlights this mode of analysis' flexibility in application – particularly in studies which draw from several data sources. Clarke and Braun emphasize this versatility when it comes to analyzing different types of data and thematic analysis' ability to identify larger patterns of shared meaning across a wider range of data sources (Clarke & Braun, 2013; Xu & Zammit, 2020). This method of analysis was especially suitable given the variety of different forms of data being analyzed for the purpose of this study including data from the physicians' focus group, survivor qualitative survey responses, and secondary data collected from FGC-related organizations and online sources. In a paper on the development of complexity theory-informed methodologies, Gear et al. (2022), argue that a complexity informed methodology and methods “allow observation of the problem from multiple standpoints” (p.7). Therefore, by including different standpoints it allowed me to produce a multilevel analysis across data collected from several different primary and secondary sources – further accounting for the study's complexity.

Similarly, as Riger and Sigurvinsdottir (2016) describe, “thematic analysis allows an understanding of complexity and context-specific variation” (p.35). By employing a method of analysis that can account for this study's complexity, thematic analysis offers a more in-depth understanding of the interconnections amongst individuals, community, and organizations. Lastly, thematic analysis can also be applied “across a variety of different theoretical frameworks and worldviews” (Riger & Sigurvinsdotter, 2016, p. p. 36) – further reinforcing its relevance to a study which employs not *only* a complexity-informed approach, but rather a combination of complementary theoretical perspectives. For example, in addition to aligning with the study's complexity lens, the qualitative method of thematic analysis is also well suited for intersectional feminist approaches. For instance, Riger and Sigurvinsdottir state, “qualitative methods such as

thematic analysis are also valued as a means of giving voice to “the other”, that is, of allowing those traditionally unrepresented or underrepresented in research to present their viewpoints in their own words, unhindered by predetermined response categories” (p.36). In order to perform a thorough thematic analysis, Clarke and Braun identify six phases which include: **familiarisation with the data; coding; searching for themes (generating themes); reviewing themes; defining and naming themes; and writing up** (Clarke and Braun, 2013, p. 4). In this section I describe my process of data analysis as it aligns with each of these six phases.

During my period of **familiarisation with the data** I implemented Creswell’s method of reading and memoing (Creswell & Poth, 2016, p. 183). The practice of reading and memoing occurs early in the data analysis stage as a means of exploring the data base (Creswell & Poth, 2016). During this period, I would repeatedly listen to the video and audio recording of the focus group, review the transcript from the discussion, return to the survey and read through the open-ended responses, reflect on conversations, read through field journal entries, and make notes to myself in the margins of the transcribed document.

After familiarizing myself with the data, I began the **process of coding**. Creswell and Poth (2016) define the process of coding as, “aggregating the text or visual data into small categories of information, seeking evidence for the code from different databases being used in the study, and then assigning a label to the code” (p.184). Each time I came across a relevant piece in the data set I would code it. This process of inclusivity in coding proved particularly important in the early stages as it is much easier to refine and or discard codes later on rather than attempting to begin from scratch and recode (Braun and Clarke, 2012, p. 61). According to Braun and Clarke (2012), “codes can also go beyond participants’ meanings and provide an interpretation about the data content...such interpretation or latent codes identify meanings that

lie beneath the semantic surface of the data” (p.61). Therefore, as Braun and Clarke (2012) describe, “codes will almost always be a mix of descriptive and interpretative” (p. 61). This practice of coding, whereby I uncovered meanings beyond the semantic surface, allowed me to begin identifying moments of resilience.

Following the process of coding, I began to generate themes. Within the context of thematic analysis in qualitative research, Creswell and Poth (2016) define themes as, “broad units of information that consist of several codes aggregated to form a common idea” (p. 186). Here it is important to note that the **generating of themes** is an *active* process and not one where “[themes] are passively waiting in the data to be found” (2016, p.9). During this period, I searched for similarities in the coded data where I began to identify larger categories from a collection of smaller codes. This stage was challenging due to the complexity at times as there were instances where I would find an overlap of smaller codes across larger themes. However, as Braun et al. suggests, moments of overlap are not unusual during this generative process and may actually help to “provide a unifying framework for telling a coherent story about what is going on in the data” (p.65). Therefore, it was not my intention to downplay the study’s complexity by appearing to minimize it through the separation and generation of themes, as moments of overlap continue to be present, and connections can still be made through this unifying framework. This emphasis on connection is further highlighted by Braun and Clarke (2012) who argue, “conclusions can and should be drawn from across the whole analysis..., so, an analysis needs to make interconnections between themes and say something overall about the data set” (p.67).

The **reviewing of themes** was a repetitive process where I returned to my data set and reviewed my emerging themes alongside what I had previously coded and collected. According

to Braun and Clarke, “this phase is essentially about quality checking” (2012, p. 65). During this period of review, I asked myself critical questions to determine if I needed to make any changes and to ensure I was identifying what was most important (Braun and Clarke, 2012). As part of this review process, it was crucial that the themes accurately captured the content of what participants were saying rather than simply describing questions that were asked (Braun and Clarke, 2012). In Murray and Chamberlain’s review of qualitative health psychology theories and methods, they note the appeal of qualitative methodologies for feminist researchers is an emphasis on “giving voice to the subjective views of women and valuing them in their own right” (2005, p.99). Therefore, this phase of review became a reflective practice to ensure that the themes identified were what was important while also staying true to the participants’ experiences.

Following this review of the themes, I began the process of **defining and naming** them. This stage is ultimately one of refinement where, according to Riger and Sigurvinsdottir (2016), “the critical task here is to identify the central idea in each theme and provide a name of which concisely captures that” (p.35). This was particularly important in terms of conveying my interpretation of the data and its meaning to the reader (Braun & Clarke, 2012). In order to ensure that these central ideas were captured accurately, several of the themes’ names were drawn from the words of participants themselves. This process of defining and naming resulted in four major themes and nine sub themes which included: politics of decision-making (anatomy, complexity, and patient choice), storyline (trauma, learning, and healing), resources (survivors, care providers, FGC organizations), and the Canadian issue.

When **writing up** the report, the selection of extracts from the physicians’ focus group, the survivors’ qualitative survey responses, and secondary public data sources was done

mindfully and intentionally. According to, Braun and Clarke (2012), “the extracts you select to quote and analyze provide the structure for the analysis – the data narrative informing the reader of your interpretation of the data and their meaning” (p.67). This concept of interpretation is especially important when outlining the analysis. Braun and Clarke (2012) argue that the analysis should move beyond the data – stating, “it does not just report words – it interprets them and organizes them within a larger overarching conceptual framework” (p.67) - in this instance, the data is then situated within the context of a combination of complementary theoretical frameworks including complexity theory, intersectional feminist theory, and multisystemic resilience in the study’s Discussion Chapter where the themes are explored in connection to these perspectives and other scholarly work more broadly.

## Chapter 5 – Findings

This chapter will outline the study's key findings. As discussed in the previous chapter, thematic analysis was performed through which four major themes and nine corresponding sub-themes were identified. The first major theme is the **politics of decision-making** (sub themes include anatomy, complexity, and patient choice) which reveals how physicians identify potential candidates for CRS, the complexity surrounding this decision-making process, and the role and influence of patient choice. The second major theme is **storyline** (sub themes includes trauma, learning, and healing) where survivors' motivations for undergoing CRS are explored in connection to the role of learning and its influence on survivors' healing experiences. The third major theme is **resources** (sub themes include survivors, care providers, and FGC organizations) where individual, organizational, and professional challenges of affording and funding CRS and its related treatment options are investigated. Lastly, the fourth and final major theme is an examination into **the Canadian issue** where the focus is on the increased demand for specialized healthcare services and what situating FGC as a Canadian issue means for the future of CRS and FGC-related care in Canada.

### Politics of Decision-making

#### *“It's not me who chooses”*

With the recent introduction of clitoral restoration surgery (CRS) in Canada, a key component to the study's aims was in understanding what types of FGC-related complications must survivors present with in order to qualify for a surgical referral; how providers identify potential candidates for surgery; and how do physicians determine who will (or will not) benefit from this procedure? To answer these questions, providers who participated in the Physicians' Discussion Forum focus group were asked about their decision-making process. When it comes

to the matter of medical decision making within the context of CRS, three sub-themes emerged: anatomy, complexity, and patient choice. Using excerpts from the physicians' focus group discussion, survivors qualitative survey responses, and secondary data these three sub-themes will be explored.

### *Anatomy*

When investigating the types of FGC-related health complications survivors must present with in order to qualify for surgical referral, it makes sense to first consider anatomy. The clitoris is a much larger sexual organ than is commonly realized with most erectile structures remaining in place after cutting. Therefore, depending on the type of cutting experienced, some survivors are unlikely to benefit from surgical intervention. For instance, if a survivor has not experienced any disruptive alterations to their sexual anatomy and are maintaining sexually satisfying relationships then it would not offer sufficient justification for them to undergo CRS.

Anatomically speaking, in order for a survivor to qualify for CRS, they would have to present in clinic with some form of FGC from which they have experienced complications that are negatively impacting their health and well-being. Dr. Deane explained how she makes that determination:

In my practice, those that are candidates for clitoral reconstruction typically don't have a visible clitoral glans...so we start by identifying what anatomy is present.

An example of this was offered by a survivor who participated in the survey component and expressed they were not interested in CRS because "only the hood was removed" and they have not personally experienced any negative health complications from this removal. According to Santos-Longhurst from Health Line, "the clitoral hood is a fold of skin that surrounds and protects the glans clitoris" (para. 1). The clitoral hood functions more as a protective covering – offering a varied level of glans protection depending on an individual's anatomy – ranging from

complete, partial, to none at all. Therefore, in this scenario, as described by the respondent, despite having experienced FGC, there would be no benefit to this particular survivor in undergoing CRS based on their anatomy and the type of cutting they have experienced.

Similarly, when discussing other instances where undergoing CRS might not be in the best interest for the survivor, Dr. Flood argued,

I think surgery is very rarely needed and if they want restoration surgery what does that even mean? And what will it accomplish? There's so much other sexual dysfunction and emotional trauma.

Here Dr. Flood highlights how the physical impact on a survivor's anatomy alone does not offer enough justification to move forward with CRS and that it is important for providers to consider additional factors that may be contributing negatively to a survivor's overall sexual function and satisfaction and/or psychological and emotional well-being. Dr. Deane explained further:

There can be a lot of emphasis on the missing anatomy and so it is just as important to identify healthy parts of their [survivors'] normal anatomy. Not everybody is a candidate for surgery. I'm finding patients often want us to have a consultation about their anatomy and an opportunity to share their experience. But there is a subset that do want surgery, some that want deinfibulation.

In an interview for Sahiyo: United Against Female Genital Cutting, Dr. Awwad reiterated similar points to Canadian physicians regarding consultations with survivors about their anatomy. Dr. Awwad stated, "it's an uncomfortable part of their body that they don't feel the same about as they do with the rest of their body. At least that's the impression that I've gotten from the women I've spoken to" (Leone, 2023).

As discussed in this section, we can see how the appearance and functionality of a survivor's sexual anatomy can be a contributing factor in a physician's overall decision-making



process when it comes to identifying potential candidates for CRS; however, it is just the first of *several* factors that physicians must consider when supporting a survivor on their path to healing.

### ***Complexity***

A physician's process of evaluation can be challenging when a survivor presents with complex needs. This matter of complexity is raised frequently amongst surgeons trained in CRS and it is a topic that was brought up during the Physicians' Forum focus group discussion. When describing the surgical techniques required to perform CRS it is often framed as a rather straightforward procedure – one which is relatively uncomplicated. However, the physical transformation via the surgery is just one aspect of a survivor's overall healing process – one that is exceptionally layered and must be taken into consideration when referring potential candidates for CRS. In addition to any physical changes, CRS can also impact a survivor's psychological, sexual, and social well-being, thus making the decision to *perform* CRS much more complex than previously conceived. Dr. Deane explained:

Yes, there's surgical technique and expertise that's involved; however, greater complexity lies in establishing the right candidates for surgery and the great importance of pre- and post-op counseling.

In order to address this complexity, it has become common practice for providers to meet with survivors interested in CRS for several consultations prior to any decisions being made on whether or not surgery would be the most appropriate treatment option. Most commonly, physicians will recommend that survivors attend a minimum of five consultations. Dr. E described what a typical visit looks like for a perspective candidate who wants CRS:

And for the surgery it's the same. We do 5 visits. But with the psychologist – not only with me. So, the first visit is really more telling their story, anatomy, a lot of sex ed. And then we do more psychological work. But they have to go through the psychological work to get to the surgery.

During these consultations there is a greater emphasis on the survivor's experience, their background, and their level of sexual education. Such an emphasis was similarly found amongst clinicians at Restore. For instance, in an interview with Dr. Awwad she noted her desire to provide her patients with as much information as possible and stated, "I usually like to explain specifically about the clitoris – the anatomy of it, how it works. We talk about reaching orgasms, how a woman reaches them, and the misconceptions that around vaginal orgasms versus clitoral" (Leone, 2023). For Dr. Deane, during these visits the topic of surgery typically accounts for only a fraction of the topics discussed throughout these initial consultations:

I emphasize surgery is not for everyone. We're surgeons – of course we love to operate, but this is your body and your story, and there are deeper layers of healing that surgery cannot address. The follow up is so important, the lead up is so important – if there is even going to be surgery. So, I really try and step back in my consultation and hear what this patient is experiencing. Surgery is one aspect we might talk about.

Here Dr. Deane notes how she tries to take a step back in these consultations – allowing survivors the space to express what it is they are looking for and what they are hoping to achieve. Such statements help to highlight physician respondents' emphasis on patient choice and patient involvement in the development of their own treatment plan.

### ***Patient choice***

Medical decision-making frequently involves not just the physician, but also the patient. This aspect of medical decision making was a common sub-theme amongst physician focus group respondents and further illustrated by survivor qualitative survey responses in terms of where survivors look for information to inform their own decision-making. When it comes to the topic of CRS, it is common for survivors to have an idea of what they want *prior* to their first clinic visit. Survivor respondents identified using different online sources like Google, YouTube, TikTok, or Reddit to learn more about CRS, reaching out to those with personal experience, or

contacting their obstetrician and gynecologist for more information. Here providers emphasized the role of patient choice when it came to discussion of CRS. For example, Dr. Deane stated:

I find that it's really from the needs of the patient. They actually say what they need and want. Sometimes they come, you know, and they're like, "I want this procedure" right? But it is definitely an exploration of what is your issue? And then we'll see if surgery might be an option. But I really do focus as much as possible on the symptoms and what their experience is because often a lot of it can come down to education.

Dr. Flood agreed:

I think being guided by what the patient wants is the best way to go.

This emphasis on the survivor's needs and the influence of patient choice was also noted by Dr. E, who stated:

It's coming from where the patient is starting and what their needs are and what they're expressing that they want. It's not me who chooses...except for the fact that they need to go through the process to get surgery if that's what they want.

The decision to move forward with undergoing CRS is deeply personal and survivors' decisions can also be influenced by their own social and cultural contexts. When reflecting on these impacts – particularly the role of family influence on patient decision-making, Dr. Flood noted that she has had several individuals on a wait list for surgery that never followed through. According to Dr. Flood,

People don't even tell their parents, even though they're in their twenties.

Due to the fact that a survivor's choice to undergo CRS is often private and deeply personal, it becomes ever more important for the provider to offer their knowledge and support to ensure that the survivor is confident and comfortable in their decision to move forward with surgery or *not* to move forward. For example, Dr. Deane described:

I'll usually say we're going to meet at least 5 times and this one is just about me meeting you, and maybe we do an examination today, and maybe we learn a little bit more. But...

I try to be like I'm here to support you in how[ever] I can support you with what I know as a gynecologist.

As Dr. Deane explained, physicians use their medical expertise as gynecologists or urogynecologists to help survivors in their *own* decision-making and offer support along the way. It is not their intention to tell the survivor what they must do, particularly in instances of elective surgery, but rather they offer survivors a safe space to share their experiences and express their needs. By being receptive to survivors' needs, providers can work alongside them to help curate a treatment plan that will be most beneficial in helping them meet their desired health outcomes. Here the role of physician, when it comes to providing this type of care, is not just a one-off encounter or limited to that of a surgical expert, but rather involves a series of in-depth meetings over an extended period of time. During this extended period, the physician takes on more of the role of guide where they help survivors along as they navigate this complex process of decision-making – one which might not even include the decision to undergo CRS.

### **Storyline**

#### ***“You need to heal your mind and your heart”***

As part of this study, I have been interested in better understanding survivors' motivations around CRS and identifying how survivors' post operative outcomes aligned with their initial expectations. Previous studies have highlighted pain relief, sex life enhancement, identity recovery, and improved body image as some of the motivations expressed by FGC survivors who wish to undergo CRS, and this study similarly found that survivors have identified comparable motivations. But as this study progressed, what I have found in Canada is that surgery (if and when appropriate) is but one part of a survivor's story, and as noted above, it is a story that might not even include CRS. In order to better explore this theme of storyline three

sub-themes have emerged: trauma, healing, and learning. The following sub-themes will be explored in that order.

### ***Trauma***

When survivors were asked what results they would hope to achieve in undergoing clitoral restorative surgery, some responses were direct and focused on the anatomical such as, “seeking improvements in clitoral sensitivity”. However, other responses spoke to the trauma that is often associated with experiences of FGC:

***“I was mutilated without my knowing. I was lied to. I don’t feel like my body is complete.”***

***“I want to get my clitoris back as it was removed completely without my consent at aged 10, when I was subjected to FGC.”***

***“To have [what] was cut off back. To feel fully complete. That I am normal.”***

Each of these responses speak to the pain, sense of loss, and trauma that many survivors experience as a result of FGC. It is often the experience of these difficult feelings that lead survivors interested in restorative procedures on their journey in pursuit of healing. As discussed in Chapter 2, individuals who experience some form of FGC may experience several health complications. In addition to these physical health complications, survivors may also experience negative psychological impacts related to having undergone FGC. These impacts can include post-traumatic stress disorder, amnesia, anxiety, concerns around body image and gender identify, depression, and mental blocks related to sexual intercourse that may result in difficulties achieving orgasm (Schrijver et al., 2016, p.270). According to Dr. E,

So many people [survivors] remember having it [FGC] done, and that hasn't been addressed...the trauma is real. I cannot count how many – it's just so many of them [survivors].

This issue of unaddressed trauma has influenced the way in which physicians formulate intake questions for their prospective patient consultations. Physicians reported finding that their patients' memory of having undergone FGC and the associated trauma is rarely discussed prior to these types of meetings. Some providers even noted the frequency in which a survivor's first time speaking openly about their experience occurs during their initial consult. For instance, Dr. Deane explained:

One of my intake questions is “who in your life knows about this?” And it is very rare that their sisters even know. Or [I'll ask] “have you ever talked to your mom about this” – no. And so, it's trying to honor that privacy for them and their own journey, while ensuring they have the support that they need to address their trauma. Some of them do exceptionally well going through a surgical procedure and it is like an awakening – a new beginning – and surgery is [a] defining moment.

Dr. Deane agrees with her colleagues stating that “there is so much to be said about the trauma piece” and explains that it is the reason why she has incorporated a minimum of five consultations for her patients before moving forward with surgery stating, “that's really become my practice”. In addition to this type of practice, the inclusion of some sort of sexual education of one's own sexual anatomy and physiology has become common place – accounting for a learning piece of a survivor's story of healing.

### ***Learning***

Dr. Seifeldin from Restore FGM argues, “many women mistakenly believe that sexual dysfunction in women with FGM results from the cutting of sexual organs, for which no treatment is available” (2016, p.1). This belief around sexual dysfunction is often the result of mistruths perpetuated by health organizations who have falsely reported that FGC can result in the *total* removal of the clitoris which, and as discussed in Chapter 2, this is simply not the case

(Seifeldin, 2016). False beliefs surrounding the practice of FGC are ultimately compounded by a limited understanding of one's own sexual anatomy and physiology. For instance, when discussing the topic of sexual education, Dr. Awwad stated, "they [survivors] don't speak to their families [about sex], they can't speak to their friends...you'll find that no one spoke to their moms either and they kind of just figured it out on their own" (Leone, 2023). It is important to note that this limited understanding is by no means the fault of the individual but is rather the result of a series of medical, political, and cultural factors over decades that have contributed to a poorer understanding of women's bodies and women's health on a global scale (Kline, 2010). This reinforces the importance of learning and the role that sexual education ought to play in a survivor's story of healing.

In reiterating the importance of sexual education during the Physician's Forum focus group discussion, Dr. Flood explained:

We're just leaning [about] clitoral anatomy or *teaching* clitoral anatomy. We never used to teach before informing patients that, you know, they haven't lost their clitoris. They've lost their clitoris glands, even a basic thing like that, showing pictures of what a normal vulva looks like or whatever "normal" is that there's such a variation.

In addition to conversations around sexual anatomy – particularly clitoral anatomy, physicians incorporate different learning tools in their practice ranging from illustrations to using a hand-held mirror as shown in the introductory chapter to help familiarize the patient with their own bodies. Another tool that physicians include in their teaching is the use of models or silicone molds of female genitalia. When explaining why she uses models in her clinic, Dr. Flood stated:

I find [them] really helpful. They really help to show patients that you know they haven't lost what they thought they lost.

Dr. E agreed:

I can't count the number of patients that I've had in the last few years who said that they had no orgasms, no sexual pleasure, no sex life because of their FGC and I examine them, and their clitoris is normal, and I can see the external glans. Everything is fine.

For survivors, the realization that their clitoris is normal, or they have not lost what they previously thought they had can be a precursor to healing – illustrating how learning can be a part of a survivor's treatment plan and overall story towards healing. In a discussion on how Dr. E helps her patients navigate any scar tissue, Dr. E stated:

It's more the education of how to stimulate it [the clitoris] and use a toy or vibrator to get to stimulate your clitoris more than to actually treat the scar I find.

This example shows that despite having clitoral cutting, a survivor may still be able to stimulate their clitoris and achieve orgasm when supported by a combination of proper guidance and tools. Again, this helps to highlight the role of sexual education and learning along a survivor's recovery journey toward healing and showcase the variety of treatment options available to survivors beyond the surgical variety.

### ***Healing***

There is often the perception amongst survivors that undergoing CRS will “fix” whatever issue they are facing. Given the complexity of addressing unresolved trauma, breaking down sexual anatomy, and learning the several causes for sexual dysfunction it may be disheartening to find that CRS is not only *not* a “quick fix” but may not even be recommended for some survivors depending on the particular needs they have expressed. For instance, in quoting American gynecologists and surgeon, Dr. Marci Bowers, Dr. Deane stated:

I'll give you new legs, but you need to learn how to walk again.



This quote stresses the point that there is no “quick fix” and even with CRS, the surgery may just be one piece of a survivor’s larger healing experience. While this initially may be a disappointing realization, what providers try to emphasize is that healing is not linear and there are many different avenues of recovery. Dr. Deane explained:

You need to heal your mind and your heart. Your body is one aspect of this [healing], and it is so layered.

This emphasizes the assorted opportunities for healing along a survivor’s journey. When psychotherapy and sexotherapy are offered, Dr. E finds that only 10% of survivors will actually proceed with CRS. When offered proper care and follow up, providers find that survivors will rarely need to go down the surgical route. While this offers insights into the various treatment options available to survivors, it is important to also review the affordability of these types of treatments.

## **Resources**

### ***“Getting those resources is the hard part”***

The issue of resources, or more accurately, the issue of a *lack* of resources was reoccurring. Survivors, FGC organization contributors, and care providers all experience the impacts of limited financial resources and thus represent the three sub-themes of the larger resources theme. For survivors, this is often in the form of being unable to afford the types of care they may benefit from, such as intensive psychological counseling, sexotherapy, platelet rich plasma injections (PRP shots), or surgical restoration procedures. For FGC organization contributors, limited financial resources can impact the organization’s ability to support survivors and can restrict their capacity for different community outreach initiatives. Lastly, for care providers, a lack of financial resources can impact their ability to *offer* the type of care that survivors may benefit from.

Fortunately, in Canada we now have some healthcare providers who are not only trained in CRS surgical techniques but have also developed an expertise in FGC-related care more broadly, yet for survivors, this path to recovery is not without costs – most notably financial. Barriers in access arise when we consider access not only in the sense that relevant and varied services exist here in Canada, and are offered by competent service providers, but also in terms of access as *affordability* of such treatments. As noted above, this issue of affordability is three-fold and exists for survivors, organizations that support survivors, and care providers.

### ***Survivors***

For survivors as prospective CRS patients it is a matter of how they can afford the types of services they might benefit from. As Dr. Deane expressed in her decision-making process, survivors who wish to move forward with CRS are encouraged to undergo multiple sessions of psychosexual counseling as part of their treatment plans. Dr. E points to the financial challenges this can impose for survivors:

They can go private for sexology or for psychotherapy, but many of them don't have enough for rent for the month, so they won't pay for a psychologist at \$120 per week, you know? And this is Montreal prices. The prices are even more in Toronto for a psychologist.

Here in Canada, we are currently experiencing a cost-of-living crisis where most Canadians are struggling to cover basic necessities like food and housing, which makes the likelihood that one could afford costly psychological counselling appointments, ranging from \$100-\$250 an hour for an appointment, unrealistic for one session let alone meeting the minimum number of appointments needed over an extended period of time, which is required for survivors who wish to undergone CRS. This was highlighted by Dr. Awwad who shared that when costs are high, it is common for her patients to discontinue their therapy sessions

prematurely when faced with financial constraints (Leone, 2023). In addition to counseling costs, survivors must also cover the cost of CRS if they chose to do so.

This is unlike other FGC-specific procedures like deinfibulation, which is covered in Canada. Dr. Deane explained:

There's a de-infibulation code within the Ontario Physician fee guide, which is significant in terms of recognition for care of those impacted by FGM/C. So, someone along the way, has advocated for FGM/C care.

The example of de-infibulation shows what is possible when there is a public push for the Ministry of Health to get a new code, because once there is a code for a procedure, people can bill for it, and it becomes funded. Dr. Deane and her colleagues are trying to push for similar momentum when it comes to covering the cost of CRS. However, in the meantime there has been some creativity in minimizing costs for survivors under different related codes, such as those for vulvar trauma or the removal of cysts for pain-related needs.

### ***FGC Organizations***

In terms of organizations that support survivors, the need for psychological supports for survivors was highlighted in an email from the End FGM Network Canada in August 2024. In an announcement regarding the launching of the organization's health care modules for care providers, End FGM Network Canada included a statement regarding a support fund for survivors. The email stated,

Recently, we have seen a significant increase in FGM/C survivors seeking immediate counseling support. Unfortunately, the number of requests has surpassed our current financial resources. We kindly invite our members and supports to consider contributing to our Survivors Fund. Your donations will directly help those in urgent need of

counseling, ensuring they receive the essential care and support they deserve (End FGM Canada Network, personal communication, August 11, 2024).

It is common for such organizations to allocate funds to support survivors; however, when an organization struggles to afford basic operations, then their ability to provide support or even participate in the facilitation of that support for survivors becomes limited.

In breaking down different dollar amounts, Sahiyo United Against Female Genital Cutting's donations webpage helps to showcase what work can be achieved by way of donation. For instance, \$50 can fund activist training, \$75 can contribute towards the provision of educational webinars for both advocates and front-line workers, and \$100 can support survivors to attend the organization's digital storytelling workshops – workshops that Sahiyo states enables survivors to “share their story and heal in a supportive group setting” (Sahiyo United Against Female Genital Cutting). Additional efforts to afford to offer FGC-related care services include packaging them alongside other initiatives as shared by Tadwein employee, Layla. By bundling various initiatives together based on similarities in association with gender-based violence (GBV) (e.g. FGC, femicide, child marriage, etc.), non-profit employees have found this method to be cost effective when funding for different projects is scarce.

Although these call to actions do not explicitly mention CRS, their efforts to provide support for all FGC survivors – particularly psychological counseling and group healing – is directly aligned with the type of treatment and care outlined by providers in the Physician's Forum focus group discussion. Therefore, funding of FGC-related organizations can directly contribute to improving the health and well-being of all survivors whether or not they are interested in CRS.

### ***Care Providers***

For care providers, it is an issue of being able to afford to *offer* care – something that I have found not only in Canada but also in countries with similar prevalence rates like Australia or even in places with some of the highest rates of FGC like Egypt (Leone 2024; Leone 2023). Providers will often have to rely on inconsistent grants from various organizations, if and when available, in order to cover clinic over-head. Others might offer their services pro-bono or rely on colleagues to do the same by volunteering their time and expertise on a needs basis. For instance, it is common for Dr. Awwad to offer her patients at least one free assessment with their clinic counsellor or psychosexual therapist (Leone, 2023). These lengths that providers go to in order to offer this type of care is admirable; however, it is not a sustainable way forward.

When asked how providers navigate the financial aspect of providing these types of services, Dr. E shared how their clinic receives funding from WAGE (Canada's Department of Women and Gender Equality) to study the health care needs of survivors in Canada:

You know in Canada, I find that it's easy to be funded for research for these subjects [FGC and CRS], but not very much for care. So, for us the foundation we get funding from [is] WAGE to study the needs of the women, so we have that funding, but they won't fund the actual care. They won't fund my psychologist who spends 4 hours a week with these women. So, that's the thing. And it's always because of the health services that are funded by the provinces. I feel that right now [the rest of] Canada may be a little bit more open than Québec for this subject.

In comparing FGC-related care and health services to urogynecology more broadly, Dr. Flood explained:

I could not do it privately because I could not pay for all the physios, the nurses, advisors, dieticians, and everything we have – that's all publicly funded...there's such a pressure to keep - to be private and paying your overhead would be tough. Just doing this kind of work wouldn't be possible.

Providers' frustration could be felt when describing the issue of finances and limited resources for this type of work in Canada in particular. Dr. E stated:

We don't have that in Canada and it's not only for FGC, it's for a lot of sexual health issues. Psychotherapy is not covered. Sexotherapy is not covered. So, we have to try to do foundations and non-profits and [get] help for people who don't have the resources. I don't think it's proper care to just offer surgery and not do the rest.

When discussing how to fund these other types of services survivors might benefit from Dr. Flood and Dr. E had an exchange:

Dr. Flood: So, getting those resources is the hard part – the personnel and the salaries – even ours, because you don't get paid a lot to see this kind of patient.

Dr. E: You don't actually...or not much. You do it because this is why we went into it...I always say you know why people do volunteer work for you know helping their society? My volunteer work is that [FGC-related care]. So, I don't go...and make soup every week. But I do that [FGC-related care] as my volunteer.

A key point that was raised in relation to the theme of resources, was the issue of demand. Currently, due to a lack of funding, providers are unable to keep up with the number of survivors looking to access their services and expertise. When discussing her clinic, Dr. E explained:

Our website for the foundation is all created – it's all there. But we did not post it, because we have a lot of demands without having it publicized. We can't have more than what we're doing right now because everything is pro bono now. So, until we get more funding for the actual care, for you know the psychologist – it's difficult for us to publicize.

When physicians are struggling to afford to offer the type of services that survivors might benefit from it impacts the availability of those services despite having competent, skilled providers with waitlists of prospective CRS candidates. Survivors, FGC-organizations, and care

providers all recognize the importance of offering this type of care and have been advocating for governmental recognition and support from the Canadian healthcare system to acknowledge this need and demand. This is what is explored in the fourth and final theme of this chapter.

## **The Canadian Issue**

### ***“It’s everywhere”***

Currently in Canada, physicians are struggling to afford to offer the type of care that survivors are likely to benefit from and survivors continue to face barriers accessing it. The fact that this is a global issue helps to highlight that it is not simply of matter of FGC is “not a Canada” issue, but rather it is a women’s health issue – one which largely impacts racialized immigrant women of low socioeconomic status and is therefore low on the hierarchy of care. The issue of demand is important to discussions of CRS and related treatment options as it helps to justify why these types of services are needed and should be made accessible and available to survivors living in Canada. The following extracts help to highlight the current issue in Canada for providers working in this care-space and some of the struggles they encounter in providing CRS amongst other associated treatment options in order to try and keep up with the demand from Canadian survivors.

When discussing options to help gain traction and momentum in Canada to increase awareness and support for FGC-related care, services, and programs for Canadian survivors, Dr. Deane and Dr. Flood reflected on previous health movements from other marginalized groups in Canada – referring to examples from provincial gender affirming care movements that were proven successful. Dr. Flood stated:

My understanding is Toronto, which now offers some gender affirmation care funding – outside of Montreal – started because of a patient advocacy group saying “why do we have to wait years and years to go to Montreal in order to get [care]?”

Therefore, based on the previous successes of similar movements, physicians noted how a community-led patient advocacy group would be the most ideal approach in terms of working to lobby Canadian health ministries for increased support. In addition to increasing healthcare supports for survivors, some providers also emphasized the importance of having more diverse providers and voices in health care spaces to better reflect the diversity of their patients. For instance, when Dr. Deane was discussing matters of cross-cultural care provision, Dr. Flood added:

It would be nice to have more providers that look like our patients because we all look white here and I think that would be helpful.

This would be especially important considering the increase of immigrant populations in Canada, particularly those from some African countries where FGC is more commonly found.

When reflecting on the current landscape in Canada Dr. Flood stated:

I don't feel like we have the same population in Alberta as we did when I worked in Ontario, because I feel like there's a lot more immigrants from Africa, etc. coming – but they seem to be younger, so my obstetrical colleagues must see them more than I do. But you know, in Ottawa it's [FGC] everywhere, in Toronto it's everywhere – more immigrants stay there and in Montreal.

Dr. Deane agreed while reflecting on her own time spent in working in Alberta during her residency training and shared that while she felt Alberta did not have the same populace as Ontario or Québec, that survivors can still be found there.

Dr. E added:

When we don't ask, we don't know, so I think there are many more [survivors] than we think.

This matter of the number of survivors has been similarly raised by FGC-related organizations like the End FGM Canada Network who stated,



We need further, deeper, and more comprehensive analyses to gain a greater understanding of the true numbers of girls and women living with the consequences of FGM/C as well as girls who may be at risk. Only then will there be the proper impetus to establish programs and services to support those girls and women (End FGM Canada Network, Canadian News).

The End FGM Canada Network has been putting pressure on the Government of Canada for years to provide official statistics on the number of survivors living in Canada (End FGM Canada Network, Impact, 2019). In September 2023, Statistics Canada released a report titled, “An Exploration of Methods to Estimate the Number of Immigrant Girls and Women at Risk of Female Genital Mutilation or Cutting in Canada”. As the study title would suggest, the purpose of this report was to investigate the potential of four methods of “estimating the number of girls and women currently living in Canada who are considered at risk for female genital mutilation or cutting (FGM/C) based on their (and their parents’) country of birth” (Statistics Canada, 2023). However, the report also states that “the results should not be interpreted as official estimate of FGM/C in Canada” (Statistics, Canada, 2023). Despite the fact the report cannot be used as an official estimate, the fact that it was undertaken at all helps to bring attention to FGC as a Canadian issue and the matter of increased demand for relevant healthcare services.

This increase in survivor populations in Canada is further reflected in the level of demand felt by providers for their expertise and services. For instance, when discussing publicizing her clinic’s services, Dr. E had expressed it is challenging as the issue is by no means a lack of need but rather a lack of funds to *meet* the need. Dr. E stated:

Most of the demands that I have are from email from people that know we exist (directly). So, I connect with the patients, and we organize their appointments.

So, here in Montreal many people from the community know that we exist. From the doctors they know that I exist. So, we have a lot of referrals, even without any publicity.

For Dr. Deane, she is in a funding model in Canada that requires a referral but is willing to see any patient affected by FGC that she can. It is common for Dr. Deane to get referrals from walk-in-clinics that will simply say “this patient has had FGC and wants to see you”. The ways in which survivors reach out to providers is varied, but one thing is clear that there are many, many survivors in Canada who feel they would benefit from their help and support.

Despite providers willingness to care for survivors and offer their services, physicians continue to be constrained by issues not only related to FGC-related care, but rather women’s sexual health more broadly in Canada. For instance, when discussing the small percentage of survivors who actually choose to move forward with CRS in Canada when counseling is offered, Dr. E noted that when proper care, counseling, and follow up is provided to patients that she finds many survivors do not need surgery. However, proper care alternatives – in this instance structured psychotherapy or sexotherapy – are not always easily accessible in Canada. Dr. E explains:

And we don’t have that [proper care and follow up related to structured psychotherapy or sexotherapy] in Canada and it’s not only for FGC – it’s for a lot of sexual health issues...it’s not just to do the surgery and then I see them 6 weeks post-op and it’s over. It’s the whole thing that comes with it. And I think in Canada we need to have more of this multidisciplinary care. Not only for FGC, but a lot of other areas.

This highlights a significant gap in Canada’s current healthcare model, where broader issues of women’s sexual health remain under-addressed – impacting not only survivors, but other marginalized groups who require specialized and ongoing care. Without a multidisciplinary healthcare model – one inclusive of psychotherapy and sexotherapy – survivors and other

women with unique sexual health needs are left with limited options, which can result in incomplete or inadequate treatment.

This chapter identified four major themes with corresponding sub-themes, each of which offers a more in-depth understanding of the complexities surrounding the introduction of CRS in Canada and the care of survivors more broadly. The theme of politics of decision-making highlights the balance between anatomy, complex cultural contexts, and patient choice in the influence of medical decision making around CRS. The storyline theme examines how trauma, learning, and healing intersect in survivors' journeys – emphasizing the emotional and psychological dimensions of recovery. The theme of resources helps to showcase the critical support systems available to survivors, FGC-related organizations, and care providers – which can significantly impact the quality and accessibility of care. Lastly, the theme of the Canadian issue reflects broader systemic challenges within Canada's healthcare landscape – particularly in terms of the availability of specialized care for women's sexual health and the need for more comprehensive, multidisciplinary approaches. In the next chapter, I will discuss these findings in more depth – analyzing them within the context of the study's complementary theoretical frameworks and existing literature outlined in earlier chapters.

## Chapter 6 – Discussion

This section begins with an analysis of the study’s main findings – politics of decision-making (anatomy, complexity, and patient choice), storyline (trauma, learning, and healing), resources (survivors, care providers, and FGC-related organizations), and the Canadian issue. Each of these findings highlight the complexity of an investigation into clitoral restoration surgery (CRS) in Canada and reveals the resilience of each demographic at multiple levels to adapt to the challenges they have encountered throughout this process. What emerges is an interconnected journey of resilience as survivors, care providers, and FGC-related organizations navigate obstacles in accessing and offering CRS in Canada along with providing general FGC-related supports and services more broadly, which attend to the intersections of survivors’ social, cultural, and gendered identities. It is through these combined efforts that incremental changes have occurred, thus improving the landscape for FGC-related care in Canada.

### Politics of Decision-making

Providers’ responses during the Physicians Forum focus group discussion along with secondary data from Restore revealed the underlying complexity of medical decision-making when it comes to identifying potential candidates for CRS. In a systems perspective, according to Petticrew et al. (2018), “complexity arises from the relationships and interactions between a system’s agents (e.g., people or groups that interact with each other and their environment) and its context” (p.2). At first glance, the issue of anatomy would appear most pressing given the fact the purpose of the surgery itself is first and foremost to restore what has been physically cut; however, as the physicians shared, anatomy was just one of *several* factors that providers must take into consideration when making their decision. Other factors that contribute to decision-making within the context of CRS include a complex intersection of individual, social, and

cultural factors. As Collins and Bilge (2020) explain, it is precisely this aspect of intersectionality, which focuses on complex social identities and inequalities, that has led to an increase of intersectional feminist-informed theory within healthcare research (p.48). In order to make the most informed decision, physicians must – alongside their patients – consider the impact of each of these identities and how they interact. In doing so ensures that care is not only specifically tailored to and sensitive of individual circumstances but also highlights the importance of addressing broader social inequities that ultimately influence survivor health outcomes.

As discussed in previous chapters, survivors who wish to undergo CRS typically identified issues related to pain management, body image, self-acceptance, and sex-life improvement as their reasons for wanting to have restorative surgery. Such issues and aspirations are usually shared with providers during preliminary consultations where prospective CRS candidates will meet with a physician and recount their story, share what has led them to this meeting, and express what they are hoping to achieve in undergoing this procedure. According to Petticrew et al. (2019), “in the case of health research, any aspect of an individual’s life could in principle be described as their ‘context’ – such as their location within any social, spatial, physical, or cultural space...moreover, the same or similar contexts may affect people in quite different ways” (p.7). Therefore, intersectional feminist theory helps to emphasize the different ways in which one may be affected by a similar context, which is relevant to discussions around decision making and CRS. Despite these similarities in context, physicians need to consider each instance on a case-by-case basis as every survivor’s experience of these factors will manifest themselves differently in their lives and bodies.

According to Brownlee et al., in their report on improving patient decision-making in health care (2012), authors state,

The patient's preference for the kind of care he or she wants is especially important when facing a test, surgery, or other treatment that is "elective." When a treatment is elective, it means there is more than one way to treat the patient's illness or condition, each possible treatment involves different trade-offs, and individual patients will view those trade-offs differently (p.3).

As Brownlee et al. describe, when it comes to elective surgeries, there may be several different treatment options available to prospective patients. For survivors, particularly those who express the desire to improve sexual functioning or sense of self, they might find that their circumstances are best aligned with *non-surgical* options – for instance, psychological counseling or platelet rich plasma (PRP) shots to improve blood flow into specific female genital sites (Restore FGM). In a qualitative analysis of health care facilitator perspectives, Amorøe et al. (2023) found, "when exploring how to deal with complexity the facilitators returned to the notion that exploring multiple possible solutions was important" (p.7). Therefore, similarly to Amorøe et al.'s findings, survivors may benefit from undergoing a combination of treatments even if those treatments do not include CRS.

For survivors who have expressed a sense of loss related to the cutting of their external genitalia, they may benefit from sexual counseling as part of their treatment plan. As discussed in Chapter 2, there is often the misconception amongst survivors that because the external clitoris was cut that the *entire* clitoris was removed – consequently fueling their desire to return their genitalia back to "normal". However, definitions of "normal" are complicated and can convey a multitude of meanings depending on the context in which they are used – whether biomedical,

sociocultural, or somewhere in-between (Rudnick, 2000). For instance, Dr. Flood's statement, "*whatever "normal" is that there's such a variation*" helps to speak to this complexity – emphasizing the amount of variation that can exist with regards to sexual anatomy, and thus bringing into question whether a true "normal" is something even achievable let alone desirable. Such discussions of "normal" are therefore intrinsically linked to the importance of sexual education for survivors – particularly those unaware of their own sexual anatomy and physiology (Leone, 2023). This lack of knowledge can contribute to false beliefs of one's own body, such as the external clitoris accounting for the *entire* clitoris as a whole. The clitoris is a much larger sexual organ than is often acknowledged – most of which is internally located and not visible to the naked eye. By working closely with a sexologist or sexual therapist, it may be possible for a survivor to achieve self-acceptance and/or a fulfilling sex life without having to pursue surgical means. However, again, this is a decision that must be made between survivor and provider.

Brownlee et al. (2012) argue, "many patients are not even aware that the decision about elective surgery is actually a choice and that it should generally be theirs to make" (p.1). Within the context of CRS, it is common for providers to offer their expertise – in this case as urogynecologists and gynecologists – to help advise survivors of the various risks and benefits of different available treatment options to ensure they are making the best choice for themselves and their individual needs. It is during this process, based on physicians' experiences caring for survivors, that survivors previously interested in CRS may decide that surgery is *not* the right choice for them and go down a different route altogether. In a review of the implications of a complexity perspective in health decision making, Petticrew et al. (2018) argue,

Complex health interventions are often characterised by their sensitivity to context, the fact that 'one-size does not fit all' and that such interventions often interact with and

sometimes adapt to the context within which they are implemented which may have implications for the effectiveness, acceptability, and sustainability of the intervention itself (p.7).

This emphasis on ‘one-size does not fit all’ is especially relevant to discussions of CRS and medical decision-making. The intersections of a survivor’s immigration status, ethnicity, and gendered reality shape their particular healthcare needs differently. As Sears (2012) explains in their study on the utility of intersectionality in understandings of cultural competency, “these multiple social locations are experienced simultaneously, are mutually reinforcing, and therefore must be considered in tandem rather than independently” (p.546). Therefore, as each survivor’s story of experience is different, it is the context of that story that will influence decisions around potential treatment options best suited to address those individual needs.

### **Storyline**

The intersection of factors that contribute to both physician and patient decision-making help to introduce the complexity of CRS which is explored in more depth via survivor and provider responses under this theme in Chapter 5. What emerges in this section by way of a survivor’s story is a journey of healing. Each survivor’s healing journey will be unique to their individual story, experience, and specific needs. Within the context of CRS and deciding whether that is an appropriate treatment option for a perspective surgical candidate, the provider takes on more of a guiding role – one where they help the survivor navigate through their personal healing journey. As outlined by the providers, and articulated by Brownlee et al. (2012), as an elective surgery, the decision to undergo CRS is largely the survivor’s decision to make. If this is a route that a survivor chooses to take, the physician will support them on that journey – providing pre- and post-operative care along the way.



Despite the relatively straight forward nature of the surgery from a technical perspective, CRS can be a longer route to healing when you take into consideration the multiple psychological counseling appointments which are required. The intended purpose of these counseling appointments is to help survivors work through any unresolved trauma they may have stored as a result of the cutting they have previously experienced. According to Bryant-Davis (2019), in their study on the cultural context of trauma recovery, “marginalized community members are more likely to experience interpersonal trauma, to develop severe PTSD, and to face barriers to safety, justice, and mental health services” (p.400). Therefore, this step in a healing journey is crucial – especially within the context of CRS as any physical transformations to the genital area by way of further cutting – including for medical purposes – is likely to bring up repressed emotions and may put the survivor at risk of re-traumatization (Buggio et al., 2019). As Dr. Deane shared in the focus group discussion, healing is layered, so to only focus on enhancing the physical body without supporting one’s psychological, social, and sexual well-being can prove impractical if not potentially harmful. This conceptualization of healing aligns with Bryant-Davis’ (2019) intersectionality-informed approach to trauma recovery care, which argues “must attend to multiple layers of identity” (p.400). Therefore, if a survivor chooses to move forward with CRS, they will not only be required to complete several pre-surgical consultations, but they will also need to continue with post operative counseling well after the surgery is performed.

As emphasized by physician focus group participants regarding their clinic experiences with survivors, the realization that CRS is not a ‘quick fix’ can be disappointing for their patients. The stories shared by providers in Canada in regard to their survivors’ healing journeys align with the experiences of physicians in countries with even higher prevalence rates. For

instance, Dr. Awwad from Restore FGM had expressed in an interview for a *Sahiyo* blog publication that survivors will often opt for the surgical route based on the belief that it will allow them to achieve their desired goals much more quickly. However, as Dr. Deane quoted American gynecologist and surgeon Dr. Marci Bowers, “I’ll give you new legs, but you need to learn to walk again”. This quote helps to highlight the complexity of challenges that survivors must overcome along their journey. For instance, if a survivor who experienced sexual dissatisfaction were to undergo CRS with the goal of improving their sexual satisfaction, it would be unlikely that their level of sexual satisfaction would improve dramatically overnight. So much of healing is involved with reconnecting with one’s body – familiarizing yourself with pleasurable sensations. Therefore, the role of sexual education and learning is paramount in helping survivors re-identify with their bodies (Leone, 2023).

Ultimately, this discussion helps to illustrate the complexity of a survivor’s healing journey. Survivors must often face unaddressed trauma, share private and intimate knowledge with their clinicians, and confront any difficulties or challenges they face in terms of body image and self-acceptance. The journey to healing is one which is incredibly challenging. Whether or not a survivor chooses to move forward with a physical transformation by way of surgery– they will certainly undergo a psychological and emotional transformation throughout this process – exhibiting a strong sense of resiliency.

A similar emphasis on resiliency and process was explored by Newsom and Myers-Bowman (2017) in their study on resilience as a journey for female survivors of child abuse. Participants in this study emphasized resilience as a process with Newsom and Myers-Bowman stating (2017), “recovery from trauma, reconceptualization of self, and the development of healthy sexuality included deliberate efforts occurring over time” (p.17). Such deliberate efforts

are observed amongst survivors along their healing journey where no part is easy. As survivors of GBV, FGC survivors are more likely to experience instances of marginalization, racism, and/or discrimination in health care settings (Heidari & Moreno, 2016; Wei et al., 2024). Therefore, making the decision to reach out for help is not easy, finding and trusting in a competent and caring provider is not easy, undergoing a series of psychological consultations is not easy, and despite these immense efforts – survivors in these instances continue to push through along their road to healing.

In DeVerteuil and Golubchikov’s (2016) discussion on resilience as a metaphor for change rather than against change, they examine critiques of resilience – one of which suggests “how resilience is used as a pretence to offload responsibility to vulnerable places and people” (p. 148). However, in response to such critiques, DeVerteuil and Golubchikov (2016) argue that researchers “tend to underestimate the degree and agency of resilience in those targeted places and people, the resolute and obstinate persistence and endurance that build on layers of previous and existing resilience” (p.148). Through their navigation of the healthcare system, vulnerability in sharing, and openness to learning, survivors have exhibited significant agency of resilience.

## **Resources**

As discussed, the road to CRS is not easy – it is the culmination of several complex decisions over an extended period of time. If CRS is the route that a survivor chooses to pursue on their journey to healing then, in addition to the physical and psychological challenges they are likely to face, it is also probable that they will encounter some financial barriers along their path. This issue of resources was a recurrent theme amongst interviews with providers and discussions with clinicians and FGC-related organizations both in Canada and abroad – further emphasizing the connection of CRS and FGC-related care more broadly to larger complex economic systems.

During the focus group, physicians highlighted the significant cost to survivors in terms of affording the type of care they would likely benefit from along with their own challenges in affording to *offer* these sorts of services. Additionally, FGC-related organizations, which often provide specialized supports for services and/or help to *facilitate* survivors' access to service providers, are also confronted with these financial difficulties.

As outlined in the resource section of the previous chapter, survivors can struggle to afford the type of care they are likely to benefit from when the median cost of counseling is beyond what the average Canadian can afford. As an elective surgery, CRS is not covered, nor are the required psychosexual counseling sessions with specialists that are necessary in order to qualify for surgery. This ultimately results in a significant barrier to care for survivors who are unable to account for these costs. When one is unable to afford these services, they are unlikely to access the quality care and support they need. Additionally, when interventions are costly, the likelihood that survivors will continue with treatment is minimal – resulting in the discontinuation of their care plan prematurely.

This need has also been highlighted by organizations who support survivors as illustrated by the End FGM Canada Network's most recent call to action. The organization put out a call to help raise funds to support survivors in need of immediate psychological counseling. Although such calls to action are not solely intended to support prospective, current, or previous CRS candidates, as FGC-affected demographics, such individuals would fall under this umbrella and could benefit from this essential care. In addition to the impact on their ability to support survivors, limited and inconsistent funding of FGC-related organizations can affect these non-profits' abilities to develop crucial educational tools and programs that seek to promote the education and cultural competency of professional frontline workers (e.g., healthcare

professionals, educators, social workers, etc.) and restricts the organizations' opportunities for community outreach.

In terms of providers, physicians with an expertise in FGC-related care are currently unable to publicize their services due to the fact that they are struggling to afford to care for their current number of patients. If physicians were to take on all the survivors on their waitlists, they would simply be unable to meet each of their needs under this current model. As discussed in the previous chapter, offering this type of care is not only *not* profitable, but it is costly for physicians in Canada when they do receive adequate support from their governing health ministries. In order to ensure that survivors are receiving the type of multidisciplinary care they need to support them along their healing journeys, physicians are having to provide their services for free and/or rely on their colleagues to do the same – particularly those in other specialized fields. Such instances help to highlight the complexity of health care today (Aburn et al., 2020). In their study on rethinking resilience amongst health professionals, Aburn et al. (2020) highlight the effects of this increasing complexity of care and the associated impacts “particularly within the context of stretched public health systems” (p.2). When overhead costs are taken into consideration along with hiring experts in the fields of psychology or sexology, it becomes increasingly more challenging and expensive for physicians to offer these services.

What becomes clear is that providers are working in this field because they believe in the importance of the work that they do, they believe in supporting survivors, and they believe in providing the highest quality of care possible. Through their commitment to their patients, the providers interviewed in this study have demonstrate a level of resilience in the face of a health care system that does not reward them for this type of work.

In a discussion of health care teams, Amorøe et al. (2023) argues, “health care teams are in themselves described as complex adaptive systems...such systems are said to be resilient if they have “the capacity to adapt to challenges and changes at different systems levels, to maintain high quality care” (p.2). Physicians have exhibited their adaptive capacity through the ways in which that have continued to provide care despite the challenges they have encountered in doing so. Additionally, physicians who have developed an expertise in FGC-related care, like those who participated in this study’s focus group, have individually contributed to incremental changes in the way that FGC-related care is discussed and understood in Canada.

### **The Canadian Issue**

When discussing resilience, DeVerteuil and Golubchikov (2016) argue, “it can be active and capacity-building rather than passive, and that it can be a necessary precursor to resistance and transformation – in short, a metaphor for change, not against change” (p.149). This has been illustrated by the various incremental changes that have occurred in Canada – particularly in the last six years – related to increased demand from survivors, care providers, and FGC-related organizations for improved FGC-related care (inclusive of CRS and its related treatment options). In order to gain further support and funding to address this growing demand in Canada, physicians focus group participants reflected on previous healthcare movements from other marginalized groups in Canada – suggesting a community-led patient advocacy group would be most beneficial in terms of garnering government support and recognition.

The strengths of such movements were similarly highlighted by Boscoe et al. (2005) in their study on women’s health movements in Canada. As Boscoe et al. (2005) state, “grassroots groups and a diverse range of citizen voices must maintain a strong leadership role as we move forward” (p.12). Additionally, in line with the issue of diversity, physicians acknowledged the

importance of having Canadian providers who reflect the diversity of their patients. As described in Chapter 2 when outlining the cultural, medical, and legal dimensions of FGC, it is common for survivors to be fearful of interactions with healthcare professionals. Due to the criminalization of FGC, survivors may be reluctant to seek out medical care or support due to fears of prosecution and/or concerns of potentially implicating their parents in a crime (Packer et al. 2015). However, it is not solely risks of criminalization that contributes to these fears, but also instances where survivors may anticipate stigmatization or discrimination. Movements to improve diversity and inclusivity within the Canadian healthcare system will help to minimize fears and improve survivors' experiences within it. Moving ahead, a leading force in these types of movements will be community members and FGC-related organizations – helping to better address the social, gendered, and psychosexual implications of FGC and the introduction of CRS (Jordal et al., 2018).

Previously considered as a practice that occurs “elsewhere” or impacts “others” – views and public opinion have begun to shift to a point where government-initiated reports on FGC are now being produced. Such advancements within our own borders have been the result of continuous efforts from providers in addition to years of advocacy and activism on behalf of organizations like the End FGM Canada Network. As the End FGM Canada Network's response to the report highlighted, this was something advocates and activists working in the field of FGC-related activism had been pushing for for years. Contributors to the End FGM Canada Network's aims and efforts have sought to situate FGC within the Canadian context to highlight the matter of FGC as a Canadian issue. Activists and advocates in this space have exhibited a process of resilience as they have worked incrementally towards governmental recognition. As DeVerteuil and Golubchikov (2016) highlight, “resilience promotes small-scale and incremental

transformation, so that resiliently alternative spaces become springboards for more fundamental transformation” (p.150). An example of this is shown by the network’s push for Canadian provinces and territories to create position statements on FGC. Another example of where organization’s resilience has resulted in incremental transformation is shown in the Canadian Prime Minister Justin Trudeau’s acknowledgement of the International Day of Zero Tolerance of Female Genital Mutilation on February 6<sup>th</sup>, 2022. In this statement, Prime Minister Trudeau affirmed his commitment to ending FGC and fighting against gender-based violence. As part of this commitment, Prime Minister Trudeau committed \$1.4 billion annually by 2023 to “support the health and rights of women, children, adolescents, around the world through global organizations and Canadian and international non-governmental organizations, including \$700 million per year specifically for sexual and reproductive health and rights” (Prime Minister of Canada Justin Trudeau 2022). This funding of organizations, which implement a zero-tolerance approach to FGC and participate in the fight against gender-based violence, further emphasizes the connection of FGC-related care to larger complex economic and legal systems. Therefore, governmental acknowledgement and funding are crucial steps in supporting organizations in Canada that champion the overall health and well-being of survivors.

As part of this investment, the Government of Canada allocated \$530,000 in funding to the End FGM Canada Network. Such funding helped to launch initiatives like the Miss Klitty project, which has helped to shape both national and international understandings and perceptions of the clitoris. Initiatives that seek to promote understanding and demystify sexual anatomy play a crucial role in improving body-image and developing self-acceptance not only amongst survivors but for all individuals with female sexual anatomy. As discussed in terms of survivors’ motivations for undergoing CRS, sexual education can play a major role in a



survivor's healing journey and can thus directly influence their decision to move forward with or without surgery. Therefore, Canadian initiatives that promote sexual education and contribute to this form of learning are intrinsically linked to CRS.

Additionally, the collaborative nature of organizations like the End FGM Canada Network have further helped to challenge beliefs that FGC is not a Canadian issue. The End FGM Canada Network has connected individuals in front-line professional fields like education, social work, law, health care, and more. In doing so, the End FGM Canada Network has worked resiliently to promote the safety, health, and well-being of survivors in Canada. In quoting Brown (2014), DeVerteuil and Golubchikov (2016) state, "this suggests the potential that resilience can be deployed in less regressive ways, 'as an organizing principle...to challenge the status quo and to design and shape alternative futures' (p. 113)" (p. 146). Through these resilient organizational efforts, FGC-related organizations have helped to challenge this status quo and realize a future that recognizes FGC as a Canadian issue.

The continuous efforts of FGC-related organizations in Canada and abroad have helped to shape alternative futures by way of small and incremental changes – transforming the futures for survivors everywhere. The work of FGC-related organizations is deeply connected to the introduction of CRS and related treatments in Canada. Efforts to enhance the visibility of FGC as a Canadian issue help to improve the availability and accessibility of all supports and services intended to improve the health and well-being of survivors. Additionally, initiatives that seek to enhance provider knowledge work to strengthen physicians' cultural competency in this area. As Sears (2012) explains, in their study on the utility of intersectionality in improving cultural competency, "understanding the ways that social locations intersect to create unique health trajectories among racial and ethnic minority patients is an important step towards improving

their health outcomes and promoting health equity” (p.550). Such advancements have been linked to improving the type of care survivors receive in Canada (Chalmers & Omer-Hashi, 2003). The more aware and knowledgeable providers are in relation to FGC related issues, the better equipped they will be to provide survivors with quality care along their healing journey and the more informed they will be to better assist survivors in their decision-making when it comes to deciding whether CRS is the right treatment choice for them.

### **Journey of Discovery**

When the major themes of this study are reviewed and analyzed, what emerges is a series of complex interconnected journeys of resilience. Prior to embarking on my *own* journey to explore the introduction of CRS in Canada, I had wanted to know why CRS was so highly contested within the medical field. I wondered if the claims were accurate, and the surgery could alleviate pain, improve an individual’s sense of self, or enhance one’s ability to achieve clitoral orgasms, then why *wouldn’t* someone want it? However, it was through my own personal journey into the study of CRS in Canada that the true complexity of this exploration was revealed.

What I found was less about the surgery itself and more about the procedure could signified – self-acceptance, sexual autonomy and satisfaction, and a sense of “normalcy”. Outcomes that I would come to learn could be achieved without any surgery at all. I had previously shared this similarly singular focus on the surgery and the promises it advertised - in awe of the ease in which urogynecologists and gynecologists could unearth clitoral glans and situate them into place. However, it is precisely this perceived simplicity that gives one the impression that CRS is a ‘quick fix’. A ‘quick fix’ for those who may have gone many years being unhappy, unsatisfied, or uncomfortable. Yes, surgically speaking CRS can be performed

quickly; however, in order to achieve the desired outcomes – the ones specifically identified by survivors, they must embark on a healing journey that has proven to be far more complex. It is a journey that involves addressing unresolved trauma related to their FGC experience, learning about their bodies through handheld mirrors and unveiling the truths of their sexual anatomy, and while surgery certainly *is* a path, what one discovers is that it is not the *only* path.

Along this journey, physicians guide their patients to help them navigate the complexity of their particular health context. In highlighting these complex processes of resilience, Njeze et al. (2020) emphasize the importance of understanding how “individual, social, and cultural processes overlap and intersect in important ways to support resilience and overall wellness” (p.2002) – further highlighting the relevance of a complementary intersectional lens. What physicians have made clear throughout this study and to their patients, is that physical health is just one aspect of overall wellness. Here physicians use their expertise not only as surgeons but as care providers to help curate an effective treatment plan unique to each survivor’s individual, social, and cultural context.

Physicians who participated in this study have demonstrated a commitment not only to providing quality and culturally informed care but have worked to make sure that this type of care can one day be accessible to everyone in Canada. Despite challenges in financing the types of treatments most beneficial for survivors, providers have been adaptive in their money raising strategies from collaborating with non-profit organizations, undertaking related government funded studies, or exhibiting creativity with different billing codes while lobbying the Ministry of Health to expand code availability – providers have been pragmatic in their approaches to improve the healthcare landscape for survivors in Canada.

In addition to the physician's journeys, FGC-related organizations can play a notable role in the expansion of CRS and related treatment options through their development and promotion of supports and services that seek to improve the health and well-being of survivors in Canada. According to Wakefield and Zimmerman (2020), "local, national, and international women's rights and gender justice movements are at the forefront of transformational approaches" (p.170). As leaders in these movements, FGC-related organizations in Canada and abroad have been at the forefront of the fight for governmental recognition. Women's right and gender justice organizations have fought resiliently for government acknowledgement of these important issues and incremental changes have occurred as a result. As Wakefield and Zimmerman (2020) explain in their reimagining of resilience supported by feminist women, "feminists have led thinking about cultural and norms change, required for system-wide transformation" (p.158). These changes may be small at first, but the effects of these impacts are buildable and can result in long lasting, wide-scale positive change.

As, DeVerteuil and Golubchikov (2016) ask, "if we cannot hold on to the gains made previously or presently, what hope have we of transforming the future world" (p.149)? The work of such organizations helps to highlight the role of small incremental changes and their impacts on the health and well-being of survivors in Canada. As Njeze et al. (2020) argue in their analysis of resilience-promoting processes research, particularly studies that draw from intersectional feminist theory, it is important that we do not neglect "to examine the intersecting individual and social factors that enhance resilience and wellness" (p. 2002). Such perspectives help to illustrate how the advocacy and efforts at multi-levels including survivors, FGC-organizations, and passionate care providers is interconnected with a shared goal of improving the health and well-being of survivors in Canada.

## Chapter 7 - Conclusion

This conclusion begins by briefly outlining some of the study's limitations related to the COVID-19 Pandemic and participant recruitment. This section is followed by a description of several of the study's strengths, which include provincial inclusions, holistic perspectives, and comparative insights. This study's main contributions to the field of FGC-related research in Canada are then summarized – particularly in the area of health. I then share some questions that I am left with that would benefit from further research and exploration before ending with a closing reflection.

### Study Limitations

#### *COVID-19 Pandemic*

This study was undertaken during the COVID-19 pandemic, which resulted in significant delays in the introduction and expansion of CRS and FGC-related care efforts for survivors in Canada. My original informant had been in the process of opening up a specialized surgical centre in Toronto, Ontario, but had experienced notable barriers in doing so. By the time a suitable clinical space was identified in the early Spring of 2020, COVID-19 had spread across the nation – putting a halt to non-emergency health care services (Sauro et al., 2023). With the suspension of non-lifesaving surgeries, this informant felt a professional responsibility to join colleagues on the front lines in the fight against COVID-19. Here this informant dedicated their time and medical expertise to helping those in hospital during the early stages of the pandemic to later taking part in Canada's large-scale COVID-19 immunization efforts by working in designated vaccination sites.

The impacts of COVID-19 shed light on the fragility of healthcare systems around the globe. Canada's healthcare system was no different, where two years following the initial

expansion of this illness, healthcare operations were still recovering – navigating provision of services in a post-2020 world. The resulting delays were longer than anyone could have anticipated, and unfortunately, after decades of service, this informant retired before they were able to open their CRS surgical centre for survivors in Ontario. This offers just one example of the effects that the COVID-19 Pandemic had not only on this study, but on the Canadian healthcare system as a whole – especially in terms of non-life saving surgeries and related community health and well-being in Canada. The effects of which can still be felt today almost 5 years later.

### ***Recruitment***

Some of the study's second limitations relate to the matter of recruitment. The challenges of recruitment were two-fold and included the issue of research participant specificity and gaining access to one of the study's demographics. Research participant specificity presented a challenge due to the limited number of potential research participants with the desired characteristics required for the purpose of this study's investigation. Firstly, restricting the pool of prospective participants in Canada to those who had previously undergone FGC limited the number of potential informants. This pool was decreased further to only including survivors who had undergone CRS or those who were interested in the procedure. As discussed, COVID-19 delayed the introduction and expansion of CRS and related surgical interventions in Canada. This delay impacted the number of survivors who had not only experienced CRS but also limited survivors' knowledge about the procedure and its availability in Canada.

Similarly, this issue of specificity also affected the care provider demographic of this study. Limiting the scope of physician participants to those with a specific expertise greatly influenced the number of eligible participants. Despite advancements in FGC-research in Canada

and community out-reach projects initiated by FGC-related organizations, there continues to be a limited number of care providers with a high-level of expertise around FGC. Therefore, limiting the pool of potential physician participants to those who not only had this expertise in FGC-related care, but also were trained in CRS, impacted the availability of potential physician participants.

The second limitation related to recruitment was the case of gaining access to one of the study's demographics. It is important to note that despite the level of perceived anonymity when it comes to participating in online surveys, due to the sensitive nature of the study topics, potential survey participants may have felt some discomfort at the thought of sharing their experiences. As noted in the focus group discussions with physicians, it is common for survivors to rarely discuss their experiences related to FGC, and therefore, it is understandable that individuals would not feel comfortable doing so in an online survey format, thus limiting the number of potential survivor survey participants.

## **Study Strengths**

### ***Provincial Inclusions***

Despite the specificity of eligible physician research participants, this study was able to include the perspectives of physicians with expertise in both CRS surgical techniques and FGC-related care across three different Canadian provinces – Alberta, Ontario, and Québec. Including the perspectives and experiences of physicians across three Canadian provinces helped to provide a more in-depth understanding of the CRS and FGC-related care-scape in Canada. As outlined by physicians during their focus group discussion, health care providers are limited by the provincial health authorities and regulations in which they work. Such limitations can impact not only which services physicians provide but also the ways in which they offer those services.

By including insights from three different provinces, this study was able to identify similarities and challenges that impact FGC-related care on a more national level.

### ***Holistic Perspectives***

In line with providing a more holistic understanding of CRS and FGC-related care in Canada, expanding the field of inquiry to include qualitative and observational data from survivors, health care providers, and FGC-related organizations helped to account for the complexity of this topic. By doing this, this approach not only provided insights into accessing CRS and related FGC health services, but also around matters of offering, educating, and facilitating those supports and services. By employing a more holistic approach to this study, it helped to highlight the interconnections between these group – showcasing the social, medical, and financial dimensions that complicate the provision and accessibility of CRS and other FGC-related treatment options in Canada.

### ***Comparative Insights***

The strength of comparative insight, nationally and internationally, was incredibly valuable in terms of recognizing issues physicians were facing when it came to offering CRS and other FGC-related health services and treatment options. Without this comparison it would have been comfortable to assume that these sorts of services and procedures were not high on the hierarchy of care simply because they are intended for individuals who have experienced a cultural practice that is believed to happen “elsewhere” and is thus not a “Canadian issue”. However, the difficulties in receiving governmental support and recognition for FGC-related care is global. This was demonstrated by colleagues at Restore FGM in Egypt who shared about the many challenges they faced when it comes to receiving adequate funding to meet the needs of their patients. Egypt is home to some of the highest FGC prevalence rates in the world and yet



their struggles to offer multidimensional care were similarly echoed by Canadian providers across each province. Whether in Canada or in Egypt, this study helped to highlight a shared struggle amongst care providers to afford to offer this type of care for survivors.

### **Contributions**

This study has contributed to a more in-depth understanding of the politics of physician decision-making when it comes to CRS in Canada. It is not a decision that is made lightly nor independently, but rather is a shared decision between care provider and FGC survivor that seeks to account for the complex needs of perspective patients. When providers consult alongside their patients to develop an appropriate care plan, they must first consider the individual's context – their physical, social, and cultural space (Petticrew et al., 2019). As understood within an intersectional feminist lens, every survivor's experience of FGC is unique and thus impacts their physical, mental, and sexual health differently. Based on these differences, a one-size-fits-all approach is not realistic when it comes to performing CRS – nor is it appropriate for FGC-related care more broadly. This study has demonstrated that any determinations are made on a case-by-case basis. By taking an individualized approach to CRS, providers are able to account for this complexity of their patients' health and well-being.

Furthermore, this study unveiled the intersections and complexities of survivors' healing journeys when it comes to CRS and related treatment options for survivors. This study outlined the various claims associated with the introduction of CRS – the surgery's ability to alleviate pain, enable clitoral sensation and orgasm, and improve issues of body image (Foldès et al., 2012). However, what was revealed, particularly through physician's accounts, was that several of the claims of CRS can be achieved without any surgical intervention at all. In recent years, researchers have emphasized the importance of offering CRS alongside other forms of treatment

options such as counseling or sexual therapy in order to be successful. Yet this study finds that “success”, in this case achieving a survivor’s desired outcome, can be achieved without surgery in many cases. This finding, shifts discussions away from CRS and towards more holistic approaches to healing. Healing is not one dimensional and, as outlined above, within the context of FGC, interventions must account for the physical, social, and cultural components to one’s overall well-being. During clinic visits, survivors should be made aware of their options and offered non-surgical forms of treatment.

Lastly, this study contributes to the limited pool of existing work that seeks to explore the issue of CRS and FGC more broadly and shed light on its relevance and importance in Canada. Despite notable advancements in the field of FGC research in Canada, particularly those led by FGC-related organizations and their associated out-reach initiatives, much more is needed especially in areas of health. Canadian FGC studies help to raise awareness about the practice, combat stigma and discrimination, educate Canadian front-line workers, and offer support in the fight for necessary services for survivors Canada. By undertaking a holistic investigation into CRS in Canada with the inclusion of insights from three related demographics – survivors, care providers, and FGC organization contributors. This study’s contribution is unique in its highlighting of how each of these three demographics are interconnected. Every study that is undertaken contributes to expanding our knowledge and understanding of FGC and its related impacts and is a step towards improving the current care-scape for Canadian survivors.

### **Questions I am Left with for Additional Research**

According to Freeman (2019), “the beauty of feminist qualitative research...we are setting ourselves and other feminist researchers up for future work, future questions, and actively changing the nature of qualitative research” (Freeman, 2019, p.15). As part of that research, I

want to share some questions that I am left with that may one day be taken up by myself or other feminist researchers for further investigation. The first question I am left with is a more explicit understanding of what the roles and responsibilities are of FGC-related organizations in terms of the health and well-being of survivors? FGC-related organizations prioritize efforts towards the prevention and ending of FGC within their local contexts as well as internationally.

Understandably, under this ethos, organizations' focus is on the protection of girls and women at risk of FGC. However, as exhibited in this study, FGC-related organizations also play a major role in the support and facilitating of survivors' access to crucial services. Additionally, as organizations in the realm of women's issues and gender-based violence, are more likely to receive governmental support and financial funding. It is important for that funding to be available to help support individuals in Canada who are living with the physical, emotional, psychological, and sexual effects of FGC. Doing so may also help to combat the medicalization of FGC by offering alternative settings to clinic-based sexual education, such as opportunities to attend community-led sexual education workshops or classes. As Flowers (2018) argues in their study on black women sex educators, "culturally appropriate, tailored interventions implemented by cultural congruent educators are key components of developing CSE [comprehensive sexuality education] programs for diverse communities" (p.319). By offering comprehensive sexual education within a more culturally appropriate setting, it may help to increase the likelihood of survivor engagement with sexual educational resources and supports.

The second question that I am left with, when it comes to financing FGC-related care services and research studies, is who "deserves" funding? How are these determinations made? This important question was raised by Restore FGM's visiting medical student from America during a conversation about resource availability and allocation in their Cairo clinic. The

increased interest in FGC-related research and restorative treatment options for survivors globally is incredibly important; however, it is also imperative that we are critical of who is receiving the funds to undertake such studies. Western countries have been at the forefront of this work in recent years with studies published out of France, Sweden, Norway (Foldès et al., 2012, Jordal et al., 2018; Jordal et al., 2019). As discussed in Chapter 2, in order to receive governmental funding, organizations must align with the stances outlined by their government institutions when it comes to the criminalizing of FGC. This raises the question of whether research in this field is more likely to receive funding and governmental support in countries where the practice of FGC is illegal, and the law is greatly enforced compared to countries where FGC is also illegal but remains widely practiced – particularly in rural areas (e.g. Egypt and Sudan).

Lastly, an area of interest for further research is that of survivor's sexual satisfaction in relation to their level of clitoral knowledge and sexual education more explicitly. In a comprehensive review of the clitoris and its role in female sexual function, Mazloomdoost and Pauls (2015) state, "a thorough understanding of the clitoral anatomy is imperative to preserving its function and maintain this important aspect [sexual functioning] of women's health" (p. 259). Additionally, in a study which explores whether clitoral knowledge translates into orgasm, Dienberg et al. (2023) argue, "sex education has been shown to increase women's anatomical knowledge, self-efficacy to experience sexual pleasure and positive attitudes toward their bodies" (p.10). These statements were supported by some of the study's findings, which emphasized the role of sexual education and learning in survivors' sexual satisfaction. It would be of great interest to compare the impacts on sexual pleasure between survivors with extensive

sexual education and those with limited sexual education to determine the influence of increased anatomical knowledge.

### **Closing Reflection**

This dissertation opened with a discussion about the “discovery” of the clitoris – briefly outlining centuries of social, historical, and medical neglect and misunderstanding through which this component of female sexual anatomy has become a symbol of resilience. This symbol mirrors the multi-system resilience exhibited by survivors, care providers, and FGC-related organizations as they navigate journeys in accessing, offering, and facilitating CRS and relevant FGC-related supports and services.

Ultimately, through the lens of CRS, this dissertation shares many stories of resilience and highlights opportunities for further discovery. As discussed in Chapter 6, the realization that CRS may not be the final destination or even a possible option can be difficult for some survivors to accept – particularly after learning more about some of the surgery’s promises. It is important to highlight that surgery is just one of many roads that survivors might explore along their healing path. Survivors may come to discover that their clitoral glans are still intact through self-exploration, a care provider might facilitate a survivor’s learning and ultimate realization that they still have an internal clitoris, or a sexual therapist might support a survivor in achieving a satisfying sex life with their partner through counseling alone. Each of these instances account for several moments of discovery along a road to healing, but unlike the historical accounts of early anatomists and linguists come to past, survivors’ stories do not end with these discoveries, but rather, these discoveries are only the beginning.

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## Appendix A – Survey Skeleton

### Proposed Survey Skeleton

#### Demographic Questions:

Q: How old are you? \_\_\_\_\_

Q: Where were you born? \_\_\_\_\_

Q: What is your primary language? \_\_\_\_\_

Q: What is your current relationship status?

Married

Cohabiting

Divorced

Separated

Single, never married

My relationship status is not listed here: \_\_\_\_\_

Q: Which of the following best describes your HIGHEST level of education?

Some high school

Completed high school

Some college/university

Apprenticeship training and trades

Completed college/university

Some graduate education

Completed graduate education

Professional degrees

Q: What type of cutting have you experienced?

Type 1 – Partial or total removal of the clitoral glans and/or the prepuce/clitoral hood

Type 2 – Partial or total removal of the clitoral glans and labia minora – with or without the labia majora

Type 3 – Infibulation – the narrowing of the vaginal opening through the creation of a covering seal.

Formed by the cutting and repositioning of the labia minora, labia major, and removal of the clitoral prepuce/clitoral hood and glans

Q: How old were you when this cutting took occurred? \_\_\_\_\_

Q: How did you first hear about clitoral reconstructive surgery? \_\_\_\_\_

Q: How long did your decision to undergo clitoral reconstructive surgery take?

Less than 6 months

1 year

2-3 years

3-5 years

Longer than 5 years

#### Ranking Question(s):



**Please rank the following from most important to least important.**

What is the largest motivating factor in undergoing clitoral reconstructive surgery?

- A) Pain relief
- B) Increase clitoral stimulation and/or sex-life enhancement
- C) Body Image
- D) Other \_\_\_\_\_

**Please rank the following areas from most impactful to least impactful**

Following the surgery, which area did you experience the most to least improvement?

- A) Pain relief
- B) Increased clitoral stimulation and/or sex-life enhancement
- C) Body Image
- D) Other \_\_\_\_\_

**Matrix Question:**

How satisfied or dissatisfied are you with each of the following?

1 – Very satisfied 2- Somewhat satisfied 3 –Neither satisfied no dissatisfied 4 – Somewhat dissatisfied 5- Very Dissatisfied N/A

1. My experience with the referral process
2. My recovery from the procedure
3. The surgery met my expectations
4. The postoperative outcomes

**Open-ended Questions:**

How have your views on clitoral reconstructive surgery changed since migrating to Canada?

Reflecting on your experience, what is one thing you wish you would have known before undergoing clitoral reconstructive surgery?

In what way(s) has undergoing clitoral reconstructive surgery improved to your day-to-day life?

Please use this space for additional comments regarding your experience undergoing clitoral reconstructive surgery.

## Appendix B – Research Survey PDF for Recruitment Emails




# RESEARCH SURVEY

## Clitoral Reconstructive Surgery in Canada

THIS SURVEY IS PART OF A STUDY TO BETTER UNDERSTAND THE INTERESTS, MOTIVATIONS, AND EXPECTATIONS OF SURVIVORS OF FEMALE GENITAL CUTTING (FGC) IN ELECTING TO UNDERGO CLITORAL RECONSTRUCTIVE SURGERY (CRS) IN CANADA.

The aims of the research are the following:

- To develop a greater understanding of survivors' interests, motivations, and/or expectations in electing to undergo clitoral reconstructive surgery
- To identify how well survivors' surgical outcomes meet their initial expectations
- To improve the referral process for survivors who wish to undergo clitoral reconstructive surgery
- To highlight the importance of quality care for survivors in Canada

This survey is open to survivors who have undergone clitoral reconstructive surgery (CRS), survivors who have not yet undergone the procedure but are interested in doing so, and survivors who have chosen not to undergo CRS. The survey is split into several sections: demographics, interest in CRS, and experience with CRS. The questions are asked in multiple choice format, some ranking, and a few open-ended questions. The estimated time to complete the survey is about **10 minutes**.

The survey will be open until May 2024. All responses will be strictly confidential. To learn more about this study, please contact the principal investigator, Kiah Leone, from the School of Health Sciences at the University of Northern British Columbia (UNBC) by email at [leone@unbc.ca](mailto:leone@unbc.ca).

To take part in the survey, please click [here](#) or scan the QR code below.



**CONTACT:**

 Kiah Leone, PhD (Cand.), MA

 [leone@unbc.ca](mailto:leone@unbc.ca)

 UNBC

## Appendix C – Research Survey Social Media Story Image



**UNBC** UNIVERSITY OF  
NORTHERN BRITISH COLUMBIA

**Research  
Survey**

Clitoral Reconstructive  
Surgery in Canada

Visit <https://www.surveymonkey.ca/r/HMTWHF5>  
to learn more or scan the QR code to participate!



**Contact:**

- 👤 Kiah Leone, PhD (Cand.), MA
- ✉ leone@unbc.ca
- 📍 UNBC

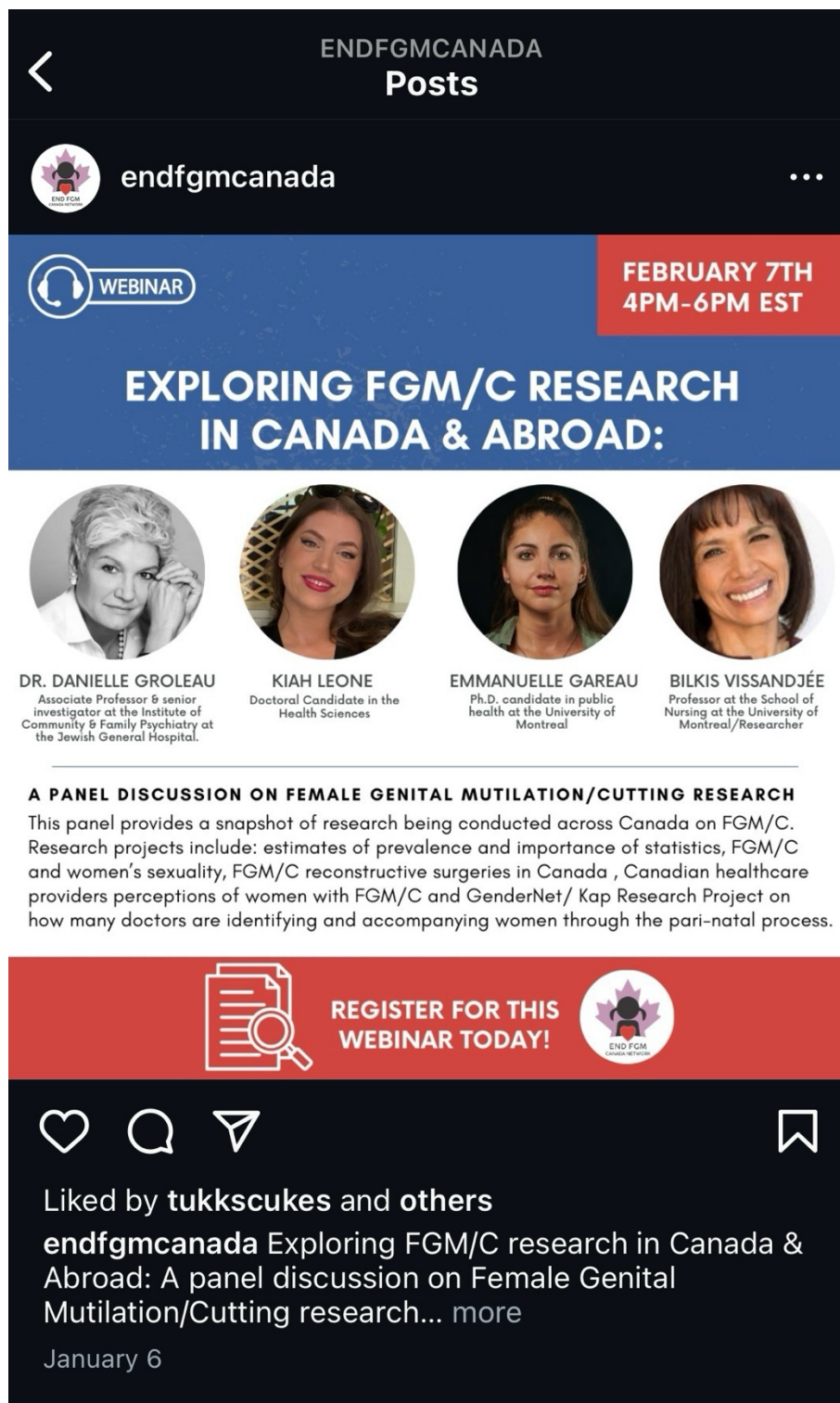
## Appendix D – Research Survey Instagram Grid Post (Sahiyo)

# Appendix E – Research Survey Instagram Grid Post (WHIWH)





## Appendix F – Research Panel Instagram Grid Post (ENDFGMCANADA)



## Appendix G – Research Survey Newsletter Recruitment Message (Sahiyo)

### Research Survey for Study on Clitoral Reconstructive Surgery in Canada



This survey is part of a study to better understand the interests, motivations, and expectations of survivors of female genital cutting (FGC) in electing to undergo clitoral reconstructive surgery (CRS) in Canada. The aims of the research are the following:

- To develop a greater understanding of survivors' interests, motivations, and/or expectations in electing to undergo clitoral reconstructive surgery
- To identify how well a survivor's surgical outcomes meet their initial expectations
- To improve the referral process for survivors who wish to undergo clitoral reconstructive surgery
- To highlight the importance of quality care for survivors in Canada

This survey is open to survivors who have undergone clitoral reconstructive surgery (CRS), survivors who have not yet undergone the procedure but are interested in doing so, and survivors who have chosen not to undergo CRS. The survey is split into several sections: demographics, interest in CRS, and experience with CRS. The questions are asked in multiple choice format, some ranking, and a few open-ended questions. The estimated time to complete the survey is about 10 minutes.

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## Appendix H – Focus Group Semi-Structured Questions

### Example Physician's Forum Semi-Structured Focus Group Questions

#### Topic 1: Physician Background

- 1.1 What is your medical background and where do you practice?
- 1.2 When did you first learn about female genital cutting (FGC)?
- 1.3 How did you begin to offer FGC-related care?
- 1.4 In your view, what makes FGC-related care unique?
- 1.5 Are you involved with any FGC-related organizations or initiatives? If so, which ones?

#### Topic 2: Canadian Context

- 2.1 How would you describe the state of FGC-related care in Canada?
- 2.2 From a healthcare perspective, what is Canada's healthcare system doing right when it comes to offering FGC-related care?
- 2.3 From a healthcare perspective, what could Canada's healthcare system do to improve FGC-related care?
- 2.4 I have heard from a number of healthcare providers that funding for FGC-related care is limited. Have you found this to be true in your experience? If so, why do you think that is and what do you think can be done to improve funding?

#### Topic 3: FGC-Related Healthcare Services

- 3.1 What type of healthcare services do you offer FGC-affected women?
- 3.2 In your experience, what services do you find FGC-affected women are most interested in?
- 3.3 What type of FGC-related health complications must women present with in order to qualify for different services? How do you make those decisions?
- 3.4 What are the financial costs of these healthcare services?

#### Topic 4: Clitoral Reconstructive Surgery (CRS) in Canada

- 4.1 When did you first hear about CRS for FGC-affected women?
- 4.2 Where and how were you trained in this surgical technique?
- 4.3 In your opinion, why do you think women are electing to undergo CRS?
- 4.4 What type of FGC-related health complications must women present with in order to qualify for CRS? How are suitable candidates identified?
- 4.5 What challenges do you face in providing CRS to FGC-affected women?

#### Topic 5: General Discussion Questions on FGC

- 5.1 What is your preferred terminology and why? (For example – FGC, FGM, FGM/C and clitoral reconstructive surgery VS clitoral restoration)
- 5.2 In the literature on female genital cutting, a lot of discussion revolves around perceptions of what is "normal". How would you define "normal"?