Rejecting Vulnerability:

Somali women's resistance to cesarean section in Columbus, Ohio

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Thank you. Thank you!

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Chapter 1: Introduction

Preamble

Columbus, Ohio. Amina Abdullah is a 29-year-old Somali woman, a proud mother of four and wife of Asad, a taxi driver in the Columbus suburbs. Amina is pregnant with her fifth child, the first to be born in the United States since her family's arrival two years earlier from Somalia via the Kakuma refugee camp in Kenya. In anticipation of the birth, the house has been cleaned, meals have been prepared and frozen, and tiny outfits have been ironed and laid out. At 39 weeks, Amina begins to experience contractions. She prepares one last meal and heads to her sister-in-law's apartment next door to wait out the pains. After twelve hours of difficult labor, Amina finally heads for the hospital, accompanied by Asad and her sister-in-law. She leaves behind Somali neighbors who had joined in the wait, coaxing Amina hour after hour to remain at home and delay arrival to the hospital. During her pregnancy Amina had been told repeatedly that she would have to fight with her provider at the hospital against a cesarean section (csection)—that it would be better to stay at home. Amina enters the emergency room entrance hesitantly. The labor and delivery doctor on-call is a woman, Dr. Schaap, which is a relief to Amina who greatly disliked the male provider she had seen for her prenatal visits. Four hours into her stay at the hospital, Amina is dilated to six centimeters. The electronic fetal monitor preventing Amina from taking a walk around the hospital—now begins beeping incessantly. A flurry of activity follows: three nurses, Dr. Schaap and a medical student rush in. All look concerned. Amina is told that an emergency c-section must be performed if the baby is to be saved. She recalls the many stories told to her over the course of her pregnancy and the advice she has been given about resisting the provider's attempts to prevent an unnecessary operation,

an injury. When Dr. Schaap asks Amina for her consent, she is ready with a response: "No". Nothing Dr. Schaap, the nurse, or the translator says will change Amina's mind. "Insha'Allah" both she and Asad say — "We will trust in God." Two hours later, the nurse disconnects a silent fetal monitor. Amina gives birth vaginally, but returns home empty handed to put the tiny outfits away, hopeful that her next birth will end differently.

Amina's story is fictional, but it is drawn from accounts of numerous Somali women who struggle to maintain control over their birth experiences in U.S hospitals. C-sections are the most common operation performed in U.S hospitals today, and rates are continuing to rise despite widespread objection from birth activists, providers¹ and women alike (Martin et al 2009). Somali women undergo c-sections in U.S hospitals at a markedly higher rate than the overall population.

One fruitful framework for understanding the differential approaches of Somali women and U.S. health practitioners to c-sections and to birth in U.S. hospitals is in terms of competing systems of knowledge. Authoritative knowledge, a term coined by Brigitte Jordan, refers to the ways in which certain kinds of knowledge are privileged in a particular environment. Irwin and Jordan (1987) write that, "a consequence of the legitimation of one kind of knowledge as authoritative is the devaluation, often the dismissal, of all other kinds of knowledge. Those who espouse alternative knowledge systems are seen as backward, ignorant, or naïve; whatever they might have to say about the issues up for discussion is judged irrelevant, unfounded, or based on superstition" (320). Somali women, like women from any other distinct cultural community, have their own practices and concepts surrounding pregnancy and birth. In U.S hospitals, these

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¹ Throughout the thesis, I refer to all medical personnel overseeing Somali births—Obstetrician/Gynecologists (OB/GYN's), Certified Nurse-Midwives (CNM's), and Family Doctors alike—with the inclusive term "Providers". When discussing Somali births in Scandinavian nations, I specifically note the presence of midwives, and not OB/GYN's at most births.

are seen to be in conflict with those of providers and the healthcare system. A host of communication and cultural barriers are manifest in the conflicts between providers and laboring women concerning perceptions of fetal rights, personhood, birthing techniques and medical interventions. At the heart of these conflicts are the differential ways in which providers and women conceive of and react to perceptions of risk and injury in pregnancy and childbirth. Disagreements with providers concerning childbearing are not unique to Somali women. However, collective negative experiences of Somali women illuminate some of the most destructive dimensions of the U.S. medical system. Rather than reaching resolution through discussion and collaboration, Somali births and U.S providers struggle to mediate their independent and often contradictory desires for a birth.

Adaptationists view health as a consequence of effective or ineffective adaptation of individuals to the environment (Singer 1990). In contrast, this study demonstrates that adverse outcomes associated with Somali births in the United States are not a result of "maladaptive" behavior. Rather, I suggest, we should view the health of individuals and communities as inseparable from the outside forces that pattern their experiences, perceptions, and choices. Merrill Singer wrote that, "critical medical anthropology' understands health issues in light of the larger political and economic forces that pattern interpersonal relationships, shape social behavior, generate social meaning and condition collective experience" (181). With this thesis, I aim to explore the forces shaping the experiences of Somali women undergoing cesarean sections (c-sections) in U.S hospitals, examining both the internal and external determinants shaping structural violence and agentive power, linking micro and macro level forces to establish a tentative map of the political economy of Somali c-sections (Sharp 2000, Singer 1990).

I begin with a basic conviction: biomedicine in the U.S is a medical culture inseparable from the capitalist and mostly Christian environment in which it was created. By examining Somali women's resistance to biomedicine's mechanisms of cultural hegemony, socio-economic stratification, and social control, I call into question what Singer (1990) calls biomedicine's "scientific' veneer to legitimize intrusions of mind and body on a massive scale" (181).

Singer (1990) concluded that the role of critical medical anthropology is to illuminate the ways in which medical hegemony and medicalization is challenged at both the individual and collective level. While it is important to reveal the resistance of Somali women to c-sections — or the culturally circumscribed actions taken by individuals to circumnavigate the perceived oppressiveness of biomedicine — it is more important to examine the ways in which certain choices become perceived as necessary, and how they are defined, disseminated and perpetuated within the Somali community. This thesis is about struggle and resistance, but moreover, it is about individuals taking an active role in their health care, defying submission to a biomedical structure that conflicts with many of their own moral ideals in search of health.

Methods and Project Description

The present project—which I refer to as the "Columbus study" for the purpose of this thesis—is based on material from a larger comprehensive study lead by Dr. Crista Johnson, named "Determinates of Health-Seeking Behavior and Health Care Utilization by Somali Immigrants." The study was created to establish understanding about the healthcare perceptions and behaviors of Somali women in the Columbus area, particularly in terms of obstetric and gynecological care. It was funded by the Robert Wood Johnson Clinical Scholars Program at the

University of Michigan and the contents of my thesis do not reflect the official policies of the funders.

The study is a community-based participatory research (CBPR) and includes 515 surveys, four semi-structured focus groups, and 15 individual interviews conducted between 2005 and 2008. My participation in the project focused on analysis of qualitative data. Recruitment was done with the use of flyers, community events, and the snowballing method. Interviews took place in women's homes, with the presence of a Somali translator. Informed consent was obtained verbally, either in English or Somali. All of the women identified as of Somali heritage, were Franklin County, Ohio residents, and over the age of 18. To elicit responses from the focus groups, a short film—*Tahara*—about a woman's dilemma concerning her daughters' circumcision, was played before discussion (Rashad 2004). Study participants received 15-dollar gift certificates as compensation for their time. All but one interview was audio recorded, per the woman's request. The interviews and focus groups were translated and transcribed only after the material was fully de-identified.

Demographics

The Columbus study consisted of 15 individual interviews and four focus groups.

Participants ranged in age from 23 to 55, with a mean age of 36. Women had spent an average of eight years in the U.S, varying between as little as one year and up to 23 years. All the women were married and were practicing Muslims. Of the 15 individual interviews, four spoke no English, six spoke some English, and five described themselves as fluent in English. All but one of the women had children, and eight of the woman had at least five children. One of the women was pregnant and expecting a c-section. Three had experiences with pregnancy complications

including inductions, miscarriages, and premature births. Of the 23 U.S births documented by the study, all but four had been vaginal births.

Most of the aforementioned demographics are appropriate only for the individual interviews, as there is a lack of relevant data from the focus groups about the demographics of participants besides their relative ages. Two of the focus groups were comprised of middle-aged women, most in their fifties, many of whom spoke little English and arrived in the U.S with multiple children. The two other focus groups consisted of young women, mostly in their twenties. These women were fluent in English and had spent at least part of their adolescence in the U.S. As a result, these participants tended to be both more highly educated and acculturated to U.S culture to a much greater degree than women in the older focus groups.

Overall, the younger and older focus groups revealed interesting though somewhat predictable comparisons: the younger generation, while aware of many of the dominant perceptions in the Somali community, looked upon on the distrust in providers and technology as uneducated and problematic. These younger women were much more comfortable in American culture, more confident in their ability to negotiate their own care, and more trusting of providers and the biomedical health system in general. "I am one of those annoying patients that likes to ask a lot of questions. I really want to know what's going on," said one young woman, born and raised in the West.

Women from the older generation, on the other hand, who largely lacked English language fluency and felt unaccustomed to American cultural norms, were more hesitant and distrustful in their experiences with providers then were the younger women. The older women were also more convinced of the need for independent action to prevent c-sections. Even though many of the older women were past the age of childbearing, their authority influenced daughters and

younger community members' expectations and actions within the informal networks of social support.

My involvement in the project

In the fall of my freshman year at the University of Michigan, I joined the research team of Dr. Crista Johnson at the University of Michigan's Robert Wood Johnson Scholars, to begin working on a project exploring the health care experiences of Somali women in Columbus, Ohio. Over the following four years I participated in various phases of the project including designing the survey questions, performing literature reviews, creating conceptual models, and undertaking qualitative and qualitative data analysis. From the beginning, c-section and the women's resistance to it drew my attention. I was captivated by the women's powerful sentiments of distrust and disempowerment that propelled their independent action against the medical system. As I continued learning and working on the project, I began noticing trends in experiences surrounding the women's relationships with providers and their eventual decisions concerning their births. I was curious to see if these experiences were indicative of a larger pattern of interactions between providers and Somali patients across the U.S.

In the summer of 2009, I spent three weeks at the Refugee Women's Health Clinic (RWHC) at Maricopa Hospital in Phoenix, Arizona, where Dr. Johnson is the current program director. The experience at RWHC was an invaluable one, allowing me to understand the intricacies of running a clinic that specifically addresses some of the constraints refugee women experience in seeking medical care. I was curious to see the differences in experience that might be possible when women felt confident in their providers' motives, hoping this might lead to more open, honest dialogue between provider and patients. During my time in Phoenix, I

accompanied Jeanne Niziyigimana, the RWHC program coordinator, on home visits with new mothers living in resettlement apartments. I shadowed both midwives and obstetricians/gynecologists (OB/GYNs) on both pre and post natal visits, and I spent time in the labor and delivery unit, experiencing first hand elements of the women's childbirth experiences I had been studying for so long. At the RWHC I observed translators and interacted with the women and their providers at the various stages of their care.

While this thesis focuses on the analysis derived from the Columbus study, it also incorporates my understandings from four years of anthropology and women studies' classes, my experiences in Phoenix and rural Mali, as well as the long-term mentorship of Dr. Johnson.

Constraints

One of the largest obstacles to work on this thesis was my lack of access to the Somali women. Due to time constraints, I was unable to participate in the interviewing process. Though I met with community members during the planning phase of the study, my interaction with the study participants was greatly limited. As a result, the vast majority of my thesis is based on secondary data analysis, interpreted by understandings gained through my experiences with the RWHC and my long-term involvement in the Columbus study. Moreover, it is imperative that I acknowledge the effect of Dr. Johnson's perspective as the interviewer. While comprehensive and sensitive, Dr. Johnson's perspective was inevitably that of a medically trained provider and not an anthropologist. As such, topics that are of interest to me as a medical anthropologist were left untouched, while other areas reveal a definite biomedical hue to follow-up questions.

Secondary analysis constrained my abilities to explore areas not elicited in the study. As a result, I was frustrated by the little material available about the role of men, social networks, and the influence of both on decision-making, which I consider critical to comprehensive understanding.

Lastly, there is a dearth of previous research regarding the birth experiences of Somali women abroad. As a result, I was limited from fully examining the Columbus experiences within a global framework by a sheer lack of material for comparison. Much has been written about the so-called inherent obstetric and gynecological adverse outcomes of circumcised women, but far less on the roots of these experiences or on the social aspect of these risks. Moreover, there is nearly a complete absence of material documenting the mechanisms of action undertaken by Somali women to avoid c-section. My research relies heavily on data from European nations because relevant research from the U.S is negligible.

Chapter 2: Introducing the major players

A brief history of Somalis in exile

In January of 1991, following 30 bloody years of oppressive dictatorship, Somali Dictator Mohamed Siad Barre was overthrown in a violent coup. In the upheaval that followed, the predominantly rural, pastoralist East African nation became the site of widespread violence and destruction, including a devastating civil war and a horrific famine. Half a million people perished, many of them children (Gardner and El Bushra 2004). Western media channels overflowed with charity commercials featuring starving children looking desperately at the cameras through fly-crusted eyes. American involvement began in August 1992, under the leadership of former President George H.W. Bush. The so-called "Mercy Missions" airlifted food and basic provisions into the countryside and were later transformed into Operation Restore Hope, which continued until 1995. The operation provided food for millions using military force to break the distribution barrier posed by warring clans (Department of Public Information, 2010).

Families and communities in Somalia were utterly destroyed and entire villages were displaced. Over 1.5 million people fled, among them many single mothers whose husbands were killed during the conflict (Garner and El Bushra 1994). Most refugees arrived at Kakuma, a makeshift refugee camp on the Kenya-Somalia border where disorder and violence continued. Close to 20 years later, many refugee camps have become a permanent home for the many hundreds of thousands for whom returning to Somalia was not an option (Upvall, Mohammed and Dodge 2009). Nearly all the women interviewed in the Columbus study spent at least a few years in the refugee camps before arriving in the U.S as part of refugee resettlement programs.

Between 1983 and 2004, the U.S accepted 50,000 Somali refugees, making Somalis the largest African community in the U.S. (Singer and Wilson 2007).

Numerous other western nations, most of them European, resettled Somali refugees. There are significant Somali communities in Denmark, Sweden, Britain, Canada, the Netherlands, and Australia. In the U.S, there are considerable Somali populations clustered around a few major cities including Minneapolis-St. Paul, Washington, D.C, Seattle, Columbus, and Lewiston, Maine (Dixon 2006). According to The Somali Community Association of Ohio (SCAO), Columbus and neighboring Franklin County are now home to over 40,000 Somali immigrants (SCAO 2010).

Rebuilding home in the Midwest-Somali acculturation

Following their arrival to the U.S as part of refugee resettlement programs, Somali families moved into a short-term, rent-free furnished apartment and received clothes, medical assistance, food stamps, and some cultural and language instruction. In the six months following arrival to the U.S., refugees were expected to begin repaying their airline tickets (Upvall, Mohammed and Dodge 2009). One middle-aged woman in the Columbus study described the difficulties of her transition to life in the U.S: "When I first came to Columbus none of my family had come here before. I came to a house with nothing but a rug and not even a cup of tea... I became very confused, with no car and no language competency. My Somali neighbors brought me dishes and helped me and brought me pots and pans and curtains and helped me to calm down and settle..."

Many of the women in the study experienced great tragedy in Somalia, losing husbands, children, and parents during the war and subsequent famine. Studies of Somali women's

experiences with acculturation document high rates of depression and anxiety following the breakdown of social support networks and the added pressures and responsibilities of single motherhood (Straus, McEwen and Hussein 2009). Following the period of subsidized housing, most families moved into low-income apartment complexes heavily populated by new immigrants, many of them Somali. Women began searching for employment out of economic necessity, defying the traditional expectation that women remain within the domestic sphere. Women detailed difficulties with finding employment that was respectful of Islam: a few cited being fired as a result of breaking for prayer, describing the experiences as incredibly hurtful: "It was hard, cried for three months...I keep getting rejected because of dress...so had to change to get a job." In Ohio, the unemployment rate for Somalis is about five percent higher than the national average, and many women expressed anxiety and frustration over failed attempts to negotiate the welfare system, fighting to receive governmental assistance (SCAO 2007).

A non-governmental organization called the SCAO seeks to help mitigate these difficulties by providing a range of services to support Somali families though their transitions, including ESL² classes, housing assistance, immigration and citizenship support, case management, and job training. The non-profit claims to have assisted over 60,000 cases since its launch in 1996 (SCAO 2010). Despite this remarkable community resource, many families still face considerable hardships. In 2006, more than 200 Somalis in Columbus were documented as homeless (Hampson 2006). According to the 2007 U.S Census demographic numbers, the Somali community is the poorest foreign-born population in the U.S. (U.S Census Bureau News 2009).

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² English as a Second Language.

Informal networks of support are a critical resource for women to share information about the availability of jobs, various available social services, and 'tricks,' little ways to negotiate life in the West. These networks of support serve to the provide a safe space for women to share their experiences and notions regarding their new lives and the difficulties they encounter during the transition to American life. Social capital has been defined as "the web of connections, loyalties, investments and mutual obligations among people" (McMichael and Manderson 2004, 89). McMichael and Manderson have documented the significant effect of social networks in the wellbeing of individuals, noting a correlative relationship between the strength of social networks and the well being of the individuals within them. Describing the dissolution of social networks among Somalis in Australia, they wrote that, "the limitations and erosion of social capital among Somalis in Melbourne restricts the capacity for social networks to facilitate processes of resettlement and promote wellbeing" (McMichael and Manderson 2004, 90). These findings are an apt description of the Somali experience in Columbus. While some women described receiving assistance from neighbors and sharing in community life through communal meals, many discussed feeling lonely and alienated in their new environments. One woman in the study explained the change: "there is no good community here to drive to because everybody is looking after their own needs. There is no, they will only do something for me if I gave them money, and I don't have money...they are not helping their own people." Indeed, much of the sharing of resources within the community that the women so fondly remembered was never regained after leaving Somalia (McMichael and Manderson 2004).

Women described the experience of childbirth and motherhood in the West as having changed considerably from previous experiences in Somalia, largely as a result of the loss of traditional postpartum community support. In Somalia, women observed a 40-day rest period

following childbirth during which family and community members provided food and childcare so that women could regain their strength. In the U.S, however, women learned that they could no longer expect any such support and must be ready to resume their daily responsibilities soon after their releases from the hospital. Women described these changes mournfully, recalling the gathering of the community to celebrate the mother and her new child in Somalia in contrast with the isolation and loneliness many mothers experience after giving birth in the West.

With support from female relatives and friends gone, and gender restrictions eased by necessity, the experience of fatherhood changed as well. Husbands began taking on new roles, accompanying women during birth and taking on new childcare responsibilities (Essen et al 2000, Wiklund et al 2000). Women described life in the U.S as scary, overwhelming, and jarring at times. Repeatedly, however, they expressed their comfort in learning to feel secure again, away from the daily terror and violence of life in Somalia and in the refugee camps. American life brought with it a host of new fears, but the women relished being able to raise their children in a nation without war³.

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³ Ironically, the 2001 terrorist attacks and ensuing Iraqi war dramatically changed the women's experiences as Muslim women in the U.S. As will be discussed in future chapters, these events shaped growing perceptions of vulnerability and intensified women's experiences with religious discrimination.

Chapter 3: Re-thinking female genital cutting

Female genital cutting is unparalleled in its ability to incite fervor, curiosity, and controversy. It is a "sexy topic" that has gained intense international scrutiny along with the wellbeing, sexuality, and morality of the cultures practicing it (Bell 2005). Within medical articles focused on Somali women, the lack of ambiguity in tone is astounding. Somali vaginas are discussed as "defective", "problematic", blamed for the long list of adverse outcomes that researchers directly attribute to circumcision. Often, when any mention of Somali women is made in medical, anthropological, and public debates, it is the state of the women's genitals that ends up gaining centrality in discussions, rather than the individual women or the influence of culture and moral judgment upon experiences. The dominant medical and public discourses surrounding the practice are often trivializing, casting a pathological shadow over entire communities of women and their bodily experiences. It is impossible to disregard the effect of female genital cutting upon Somali women's experiences with birth, but it is important to look beyond physiological determinants. I believe the imbalanced imposition of Western morality in the U.S which regards Somali women's bodies as "repressed", "de-sexualized," and "mutilated" powerfully directs the forces shaping Somali women's adverse experience with birth in the West, perhaps even to a larger degree than the actual circumcision cut.

When writing this thesis, I was wary to participate in the always-contentious subject of female genital cutting but was deeply aware that any discussion of the birth experiences of Somali women in the U.S that did not include the effect of circumcision would be dishonest. I find the over-generalized, condemnatory declarations of moral judgments by medical providers and the mass media to be problematic and unsettling, revealing massive cultural insensitivity and at times even racism. Ellen Gruenbaum (2001) describes my position well when she writes, "to

offer or impose change rooted in the various values and cultural traditions of powerful external forces constitutes *cultural imperialism*" (emphasis added, 29).

The following chapter seeks to inform readers about the practice of female genital cutting, but more so, my goal is to provide a more complex, critical understanding of the practice, its roots, and influence. By revealing women's experiences with their own bodies and with others' reactions to it, I hope to provide a gateway to a re-evaluation of the meaning of circumcision and the ways in which it influences Somali women's lives in the West.

A rose by any other name? tracing the changes in terminology

Female genital cutting refers to procedures involving the medically unnecessary partial or complete removal of external female genitalia (WHO 2010). An estimated 100 to 140 million women have been circumcised worldwide, with some three million girls circumcised each year (WHO 2010). The practice of female genital cutting spans hundreds of years and thousands of miles, over a wide geographic and cultural expanse, from Malaysia to Sudan and Eritrea to Lebanon. There are significant differences among these various cultures and nations in terms of how female genital cutting is practiced, understood, and perpetuated. In most nations where the practice is widespread, it is generally referred to as "tahara," a word derived from the Arabic word for purification, referring to the state of purity achieved through the circumcision of women. Taking into account the ability of words to bear meaning, female genital mutilation — the most common English term for the practice — is hardly a concealed statement of moral judgment.

Western terms defining the practice have changed considerably during the last 40 years and are powerful reflections of the changes in Western discourse and approach to it. Initially, the

practice was termed female circumcision, a symbolic link to male circumcision, which is commonly practiced worldwide, including Somalia. Little was known in the West about female genital circumcision until the early 1970s, though some documentation by early explorers and missionaries reveals roots of Western voyeurism onto the practice. Female genital cutting was mostly relegated to the pages of *The National Geographic*, where it served as an example of "exotic" traditions alongside other ethnocentric, racist documentation of "primitive" lifestyles (Shell-Duncan and Hernlund 2000).

In the 1970s, corresponding with the development of the Women's and Civil Rights movements, dissent against the practice gained momentum and widespread international attention. The United Nations (U.N.) and World Health Organization (WHO) adopted a new term, female genital mutilation, to reflect the standpoint that regarded the practice as deliberately brutal. Dissent and public outrage against female genital cutting began taking center stage in Western academia, mass media, and Feminist groups; female genital cutting became the new "hot" controversy, center of many charged debates concerning morality, international human rights, women's empowerment, medicalization, and Western imperialism. Bettina Shell-Duncan and Ylva Herlund (2000) eloquently describe this change in attitude: "a reclassification has taken place: the local has become a global concern...a 'traditional practice' has become a 'human rights violation'" (1).

While the public often uses the terms female genital mutilation, female circumcision, and female genital cutting interchangeably, many understand, as I do, the choice in terminology to be an intentional statement of positionality. Communities that practice or historically practiced circumcision, both in Africa and in the West, have expressed great dissatisfaction with the term female genital mutilation, which they understand to be patronizing, overly judgmental, and

stigmatizing (Gruenbaum 2001). Ellen Gruenbaum, a medical anthropologist who studied female genital cutting, particularly in Sudan, detailed the concept of "second circumcision" in referring to the negative effect compounded upon Somali women by stigma and public scorn which can lead to further discrimination towards circumcised women. If young women raised in the U.S are told to expect sexual intercourse and childbirth to be terrible, and are "prepared" by a variety of insensitive outlets to believe that they are victims of their parents' "mutilation", reality may become a self-fulfilling prophesy (Gruenbaum 2001, Gruenbaum 2009). In this thesis, I have intentionally chosen to use the terms female genital cutting and circumcision, and will refer to the women as circumcised.

Types of female genital cutting

The WHO (2008) recognizes four major types of circumcision, each of which is associated with different risks and reasoning:

Type I — Partial or total removal of the clitoris and/or the prepuce (clitoridectomy).

Type II — Partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora (excision).

Type III — Narrowing of the vaginal orifice with creation of a covering seal by cutting and appositioning the labia minora and/or the labia majora, with or without excision of the clitoris (infibulation).

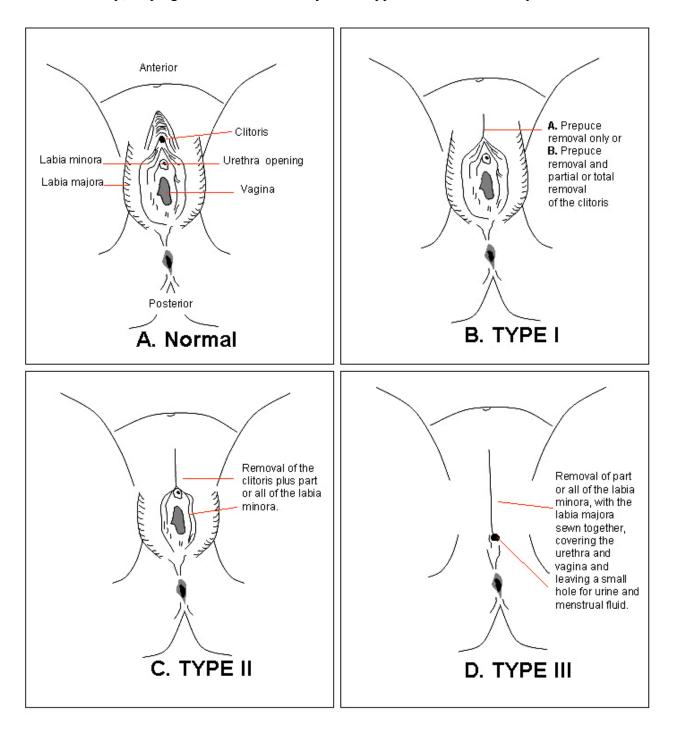
Type IV — All other harmful procedures to the female genitalia for non-medical purposes, for example: pricking, piercing, incising, scraping and cauterization.

The following diagram, delineating the four major types of female genital cutting, was created by Toubia (1999) and is published by RAINBO⁴. It was instrumental during the

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⁴ Research, Action and Information Network for the Bodily Integrity of Women.

Columbus study, helping the women to identify which type of circumcision they received.



The WHO terms, while helpful in unifying and standardizing various traditions, are medicalized and do not allow for diversity and nuances between categories. Among many

circumcised women, including those in the study, Type II is often referred to as a "Sunna" circumcision, a word translated as "tradition" from Arabic. The term references the supposed link between circumcision and Islam, and for the most part refers to type II but may also colloquially include type I and IV. Similarly, type III, medically known as "infibulation" is called a "Pharonic" circumcision, a term which is said to be a vestige of the roots of the practice, thought to have begun in Ancient Egypt, where it served to ward off rape along trade routes (Shell-Duncan and Hernlund 2000).

Somalia has one of the highest prevalence rates of female genital cutting worldwide, along with Sudan, Eritrea, Mali and parts of Kenya and Nigeria. According to the WHO (2006) estimates, 98 percent of Somali women between the ages of 14 and 49 are circumcised, 80 percent of them with infibulation, which is understood as the most severe form. Among the women in the study, the vast majority of older women had been circumcised with the Pharonic type, whereas the younger women mostly received Sunna circumcision. These disclosures may be partially inaccurate, as a result of women's growing awareness of the harsh moral judgment against the practice in the U.S, and their desires to preemptively avoid scorn (Gruenbaum 2009). Thus, Gruenbaum claimed, women may self-identify as having a Sunna circumcision, or they may call a daughter's circumcision Sunna, regardless of the actual physical severity of the circumcision.

Memories

Circumcision in Somalia typically occurs before puberty. Among the women in the Columbus study, most were circumcised around the age of five. Circumcisions are traditionally performed by women from the village, either by midwives or by the girl's grandmother. It is the

mother or grandmother of the child who typically direct the circumcision, and despite Western perceptions, men have little function or clout in upholding the tradition. The women in the Columbus study who shared their experiences with circumcision revealed a variety of nuanced stories — some nostalgic, others bitter. Many of the stories the women told included memories of intense pain and fear. A few women spoke of being lured by grandmothers and mothers with the prospect of candy and games, only to be traumatized when razors were produced instead of treats. One older woman who underwent a Pharonic circumcision at the age of eight recalled that, "one time I was playing with some other children and my mother told me she would bring me candy....I was then taken by my mother to a woman's house with many knives and needles and they grabbed me and opened my legs."

Many of the stories found in Anthropology journals and Western media seem to indulge readers with nightmarish narratives, relishing in gory details and photos of unsanitary circumcisions. This particular way of describing the practice seems to serve the voyeuristic purpose of public consumption and anti-FGC advocates, but not necessarily the women who actually experienced the events. Fuambi Ahamadu, one of the leading researchers on the sexual experiences of circumcision women wrote, "can it possibly be a good thing for thousands of African immigrants who must soak in images of their nether regions literally spread open in 'education' pamphlets, women's magazines and so-called documentaries for the modern world to ponder?" (1995, 46). These types of stories do not represent the entirety of circumcision experiences in Somalia and are an over-generalization that influence the kinds of experiences Somali women have with Western providers whose main source of information about circumcision stems from medical journals that reproduce this view.

Not all of the women's narratives of their circumcisions included terror and trauma. For some women, circumcision was an occasion to be looked forward to with great excitement and anticipation. A few of the women in the Columbus study spoke of their circumcisions in ways that belie the assumed negative psychological effect of female genital cutting. One woman remembered that, "I used to beg my mother to do it, like, 'Mommy, when is it going to be time?'...When my time came I was just so happy."

Socio-cultural and religious context for circumcision in Somalia

The WHO details five central rationales for the practice of female genital cutting: social pressure, promotion of proper sexual behavior, ideals of beauty and cleanliness, religion, and upholding tradition and cultural unity (WHO 2008). Often, these divergent rationales are overgeneralized and treated as uniform across regions where circumcision is commonly practiced, whereas there are vast differences in the importance of and motivation for practicing circumcision cross-culturally (Shell-Duncan and Hernlund 2000). Among the women in the Columbus study, religious reasons, beauty, and maintenance of virginity and fidelity proved to be the most salient.

The relationship between Islam and female genital cutting is often contested. There is a growing argument, revealed in the statements of many women in the study that refute the supposed Islamic mandate of circumcision:

FGC is something that causes problems. There is no benefit to it. In our religion, something that causes problems is haram [unlawful in Arabic]. FGC is not part of our religion. Our religion is against it. People with no knowledge did it. Men who understand the religion do not have their daughters cut.

In fact, the vast majority of Muslim religious leaders advise against the practice. Despite this, many Somalis quote the prophet Muhammad as having said to a circumciser, "Do not cut too

severely as that is better for a woman and more desirable for a husband' (CMJE 2007). Some Somalis point to the Islamic roots of the practice of Sunna and the necessity for its perpetuation because of this quote (Gruenbaum 2001). One woman, explaining why she chose to circumcise her daughter differently than herself, stated, "I did not do Pharonic circumcision on [my] daughter, but the flesh [clitoris, prepuce] on her, I had it cut off. I did Sunna on her...Because that flesh is prohibited in Islam...so [I] cut off a little bit of it".

Despite trends towards abandonment and mitigation of the practice in Somalia for the past century, women in the study discussed the overwhelming social pressure to circumcise daughters that existed at the time they themselves were circumcised. Women spoke of circumcision in terms of honor, a continuation of family and cultural traditions. A study of the health care perspectives of Somali immigrants to the U.S similarly discussed women's intense fears that their daughters would not be married if they were not circumcised (Upvall, Muhammed and Dodge 2008). In a nation where virtually every woman was circumcised, a family's decision not to circumcise daughters brought with it the wrath and scorn of community members.

Many study participants from Columbus recalled women commonly insulting each other by referring to each others genitals as "uncircumcised," calling them "ugly", "open", and "flapping". Women spoke of the intense social pressure to circumcise their daughters, thus preventing the emotional harm that such a denigrated status might bring to their daughters. From the perspective of social harm reduction, circumcision would not relegate their daughters as social pariahs, exposed to the scorn and mockery of the community while simultaneously risking their future marital success. Women recalled that children used to insult each other if they were

not yet circumcised, causing young daughters to run home and request it from their mothers: "they want it to be done. They ask for it...it's not something that is forced upon them."

In Somalia, the major rationale for the practice hinges upon the immense desire for virginity at the time of marriage. Circumcision provides a visual confirmation of the purity of daughters and future wives. It is an assurance of marriagability. "People didn't marry woman who were not circumcised," said one woman. Circumcision was understood to act in two ways to guarantee virginity and fidelity. First, circumcised women are seen to experience pain during initial intercourse or at least to have reduced sexual desire, and are thus less inclined to engage in sexual promiscuity. Secondly, since most women with Pharonic circumcision need some level of surgical intervention before they are able to engage in intercourse, families are able to provide unquestionable confirmation of a daughter's purity. In fact, as one woman stated, if a woman had "only" a Sunna circumcision, it could be assumed that she was no longer a virgin or that she has been improperly circumcised.

Circumcision acts as insurance against promiscuity: daughters could be relied upon to remain virgins, and wives whose husbands departed for long periods of time could be trusted to remain faithful. One woman in her late fifties stated that, "the circumcised woman is inactive [sexually], so she will stay at home. The uncircumcised, she has a lot of feeling, so she will run away with a man and have a child out of wedlock. Causes distress for family." Somali marriages were often very purposefully chosen for the ties they created between families and villages. Circumcision helped ensure that the sexual ripening of teenage daughters did not interfere with these plans and that male lineage could be maintained.

Another rationale for the continuation of female genital cutting in Somalia rests upon its aesthetic qualities. "It's kind of like an ugly thing to have it open," said one woman who is

Pharonically circumcised. Another, compared circumcision to clothing, claiming that it helps to keep women covered and modest, preventing vaginas from "flapping in the wind." In a discussion surrounding the desires of some women not to be re-infibulated⁵ following vaginal births, many women responded incredulously, claiming that bugs and ants would crawl in their "uncovered" vaginas.

One middle-aged woman stressed that as opposed to foreigners focusing on the health problems posed by circumcision, Somalis think of the procedure in terms of beauty and honor. She discussed the aesthetic merits of circumcision in terms of a culture-specific practice of self-beautification, not unlike some of the procedures undergone by women in the U.S. This reasoning is not unique to the women in the study, and has been discussed among scholars who compare the practice of female genital cutting to the numerous procedures that Western women undergo routinely, from waxing and breast enhancement surgery to the growing trend of labioplasty (Bell 2005).

Most women spoke adamantly about their trust in the beauty of circumcision. "American doctors have to tell the truth" one older woman added seriously, turning to the American OB/GYN interviewer and asking rhetorically, "who is better looking? Forget about talking about health complications or birth... ours is hidden and closed nicely, but they [uncircumcised women] are just open and you can see the bad stuff. Which one is more beautiful?"

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⁵ Re-infibulation refers to the surgical procedure of physiologically re-closing or restoring the vaginal opening to its pre-episiotomy state following childbirth. Since no standardized medical guidelines exist, HCPs often must rely on their own moral judgment in deciding whether or not to abide by the wishes of patients. Some understand the procedure to be wholly medically unnecessary, implicit approval of circumcision. Others justify the procedure by acknowledging the consent of the women to the procedure and the psychological damage that may be caused as a result of social exclusion or rejection by partners (Baker et al 1993, Theirfelder 2005). Many women in the study described their anger at not having HCPs discuss the decision or whether or not to re-infibulate them, regardless of the women's stance. For many Western HCP's, the question of re-inifibulating patients upon request is one of toughest ethical dilemmas they face (Theirfelder 2005).

Regardless of their position toward circumcision and the question of its perpetuation in the West, most women were pragmatic in their positions toward the beauty of their own circumcision: "in Somalia they [circumcised women] view themselves as beautiful and in America they still do because they went through it. It's not like they can go back."

Changing attitudes

The dissolution of many family and clan ties during the civil war and ensuing cultural upheaval brought many changes to family unity and traditions, which have in turn affected the practice of female genital cutting. Immigration to Western nations resulted in a wide range of changes to the community support behind circumcision, as well as to the viability of the continuation of the process. Morison et al (2004) stated that social assimilation wrought changes in beliefs about sexuality, marriage, and religion, which in turn reduced the cultural importance of circumcision. The study, an exploration of Somali acculturation in London, reported that as members of the community became socialized in Western culture, they became more apt to abandon the practice.

The most immediate barrier to circumcision following immigration to the U.S. was its legal status: as of 1996, female genital cutting is considered a federal offense. While there had been several Somali governmental attempts in the 1970s to ban circumcision, these had minimal effect on the actual practices in small villages. The repercussions in the U.S, on the other hand, are understood as very real. As such, a few of the women discussed fear of arrest as motivating the abandonment of circumcision.

The women in the study spoke of the ways in which their conceptions of their own circumcisions have changed as a result of exposure to other cultures and to the larger discourses

surrounding circumcision. They explained that in Somalia they had continued Pharonic circumcision out of ignorance, but that now that they have become more educated and exposed to the possibility of not circumcising women, they have changed their minds. "When in Somalia didn't know any other practices or no knowledge of how women without circumcision feel. Those of us who were circumcised…learned the new [practices]. In Somalia you were happy because you didn't know nothing else, but when in different country you realize different practices. We're angry, and younger generations stop the practice."

For most women, the change in position towards circumcision was explained as stemming from a growing understanding of the potential physical harm posed by it in terms of obstetric and gynecological complications. Despite their awareness of such problems even before moving to the West, the women cited a lessening of social pressure to circumcise that led them to re-evaluate the practice and its possible effects. "People understand that without circumcision, the girl will be alright [no health problems], the couple will be happy and enjoy each other, and when she is delivering babies, she will not have all the complications that a circumcised woman will have. Vagina looks beautiful not cut, way God created."

Changing beliefs about sexuality and marriage were also seen to affect women's new positions towards circumcision: "culturally they used to believe that they were beautiful because they thought it protected their virginity. And so you could trust them... now we know—everything comes from woman's personality about promiscuity and not from circumcision. It doesn't affect them or help them to stay virgins but it will lessen their desire."

With the changes in stance among Somali women following immigration came simultaneous changes in terms of men's preferences. Whereas in Somalia women were understood not to be marriage-worthy if they were not circumcised, the women reported that this

preference has not been sustained by the move to the U.S. Preferences are changing, particularly among younger men. "Circumcision is not something that will attract or not attract a man," said one woman in her mid-thirties. "A man will marry whom he want to." Women spoke about the gradual inclusion of men into awareness of the complications and pain circumcised wives experience during intercourse and childbirth. As a result, the women explained, many men have now come to oppose circumcision of their daughters. Moreover, younger men are increasingly making the choice to marry uncircumcised Somali women. "The man wants to enjoy his wife and he can't open her for himself...so they do prefer women to be open." Although the study did not include men, a similar qualitative study about assimilation and attitudes towards female genital cutting found responses elicited by Somali men to match those of the women in the Columbus study (Morison et al 2004).

"But just a prick": on circumcising daughters

Because many of the women in the study raised daughters in Somalia and Kenyan refugee camps amidst social unrest, decisions these women made about circumcising their daughters before arriving in the United States make for an exceptionally interesting case study. I postulate that because of the social unrest and breakdown of clan and family ties during the war, the social pressure to conform to the Pharonic circumcision was lessened, allowing individual families to make choices concerning daughters' circumcisions. The women's narratives reveal a gradual shift from Pharonic to Sunna circumcision. In the Columbus study, many of the older women spoke about how their generation was almost entirely circumcised with Pharonic, but that their daughters were circumcised with Sunna to correspond with a growing preference for a less severe form of circumcision. In fact, almost all the women in their 20s and early 30s had Sunna

circumcisions. This is a trend the women claim is taking hold in Somalia as well as the Kenyan refugee camps, and it is corroborated by a similar study of Ethiopian and Eritrean immigrants to Sweden (Johnsdotter et al 2009). Some women discussed deciding to perform Sunna on their daughters to prevent them from having to experience serious health complications. A qualitative study from Sweden reported similar health explanations for the abandonment of female genital cutting abroad (Johnsdotter et al 2009).

Men were also seen to be more involved in decisions surrounding daughter circumcision.

One older woman discussed her husband's support of the decision to not circumcise their daughters at all as stemming from his awareness of the pain she experienced. "I don't want her to go through what I have to go through. I wouldn't have done it if they had given me a choice."

Many women shared the same rationale. Given the choice not to have to circumcise their daughters with the Pharonic circumcision, they happily had either a Sunna circumcision performed or nothing at all. "Culturally, we are against it now" concluded one woman in her mid-fifties.

The harm done? the misinformation about gynecological and obstetric sequelae

The topic of female genital cutting and its health complications is controversial. In 2006, the WHO reported that there are medical risks inherent in *every* type of female genital cutting (Banks et al 2006). There is no doubt that the procedure has the potential for many immediate and long-term health complications. However, when Western researchers and providers discuss circumcision complications, extreme scenarios are often publicized as commonplace and discussions surrounding them become overly simplified, leading to misunderstanding and misinformation. It is important to note that the vast majority of data available about obstetric

outcomes for women with circumcision was gathered in Africa and not in the West. Thus, figures pertaining to risk of complications do not take into account the experiences of immigrants to the West and the reduction of complications brought about by increased access to biomedicine. The purported universal complications are, in reality, much less applicable to those with access to improved medical care (Ahmadu 2009). In fact, there is very little data available concerning the obstetric and gynecological sequelae of women in Western hospitals, and the little that is available comes mostly from Scandinavian countries, where healthcare is provided for all, midwives oversee most low-risk births, and access to healthcare is remarkably high. Despite the significant differences between the U.S and Scandinavian healthcare systems, there are important links between births in both environments. Norway and Sweden have some of the lowest rates of maternal mortality in the world and by most accounts, obstetric services there are superb (Unicef 2010a, Unicef 2010b). Yet even in Norway and Sweden, Somalis have a much higher rate of adverse outcomes than do native-born populations. By examining Somali women's birth outcomes and experiences in some of the most advanced medical systems in the world, important revelations can be made about their care in the inadequate healthcare system in the U.S.

It is important to note the ways in which so-called "scientific" medical data facilitates misunderstanding about circumcision. Most of the medical articles on obstetric and gynecological sequelae do not distinguish between the various types of circumcision. This is a critical misstep that overlooks the drastic differences between types of circumcision and their associated risk of complications. In terms of adverse outcomes, Pharonic circumcision poses far greater risks by affecting the vagina and urethra directly, whereas the Sunna circumcision leaves the vaginal opening unchanged. When medical statistics fail to mention these differences,

circumcision is fallaciously presented as uniformly "problematic". Nevertheless, circumcised women do experience obstetric and gynecological complications, though at less severe rates than many studies suggest.

Women with Pharonic circumcisions may experience chronic complications such as recurring bladder and pelvic infections, cysts and keloid scar formation, menstrual and urine blockage, and infertility. The circumcision also requires surgical re-opening, or de-infibulation⁶, before intercourse and during childbirth (Braddy and Files 2007, DeSilva 1989, Newman 1996, Vangen et al 2002, WHO 2008). Women with Pharonic circumcisions are also at higher risk for obstetric complications including emergency cesarean sections, episiotomies, fistulas, perineal tearing, post-partum hemorrhaging, prolonged second stage of labor, and fetal distress (Braddy and Files 2007, DeSilva 1989, Dirie 1992, Essen et al 2000, Newman 1996, Vangen et al 2002, WHO 2008). On the other hand, women with Sunna circumcisions are at risk for developing some of the immediate complications stemming from unsanitary conditions or improper technique that include shock, infection, swelling, and bleeding but are largely exempt from all other complications (Chalmers and Hashi 2000, Dirie 1992).

Secondly, the risks posed by circumcision are directly affected by the environment in which it takes place. In small villages, female genital cutting is often carried out by non-medically trained practitioners using razors, shards of glass and knives, usually without the use of anesthesia. In contrast, many circumcisions that take place in cities occur in sterile environments and are preformed by medical personnel using local anesthesia (Braddy and Files

⁶ De-fibulation refers to the surgical opening of the vagina of circumcised women. This procedure is sometimes preformed at the time of first sexual intercourse to allow vaginal penetration, and is a fairly standard procedure in preparation for vaginal birth, taking place either during childbirth or increasingly during the second trimester of pregnancy.

2007). Moreover, even within secluded villages, changes are taking place regarding the risks associated with circumcision⁷.

For the vast majority of women in the Columbus study who experienced adverse health as a result of circumcision, health issues arose during the time of their first period and at childbirth. Three of the women experienced recurring urinary tract infections and kidney problems, while others describe slow and painful urination. Many of the women also experience painful periods and menstrual blockage⁸. Women also experienced pain as a result of being opened and re-closed for each birth. However, the women were quick to point out that most of these complications were mediated by the faulty providers who caused excessive scarring, and not inherent in the practice. Studies of Somali refugees in New York and Florence, Italy reported rates of long-term complications similar to those discussed by the women in the Columbus study, that is, a low prevalence of severe complications alongside higher rates of pain during menstruation and intercourse (Arbesman, Kahler and Buck 1993, Catania et al 2007).

An important study from Norway examining the differences in obstetric sequelae among immigrant groups revealed that even in comparison to other vulnerable groups of women, Somali women have higher rates of neonatal death, low APGAR⁹ scores, and a c-section rate twice as high as that of the Norwegian-born population. The researchers attributed these results to high rates of fetal distress and to a lack of experience among providers with de-fibulation of circumcised women (Vangen et al 2000, Vangen et al 2002). This confirms some of the Somali

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⁷ As part of a multitude of harm-reduction and abolition interventions taking place throughout regions of circumcision practices, razor exchanges are being set up. Much like needle exchange programs for heroin addicts in the West, circumcisers are being given clean razors, disinfectant, and local anesthesia in an effort to greatly reduce the immediate complications posed by circumcision (Gruenbaum 2009).

⁸ This refers to menstrual blood trapped inside a woman's body due to the fact that her circumcision scar tissue healed in a way that completely closed off the entrance to her vagina.

⁹ APGAR is a standardized method used to assess the wellbeing of newborns. The acronym stands for five criteria-Appearance, **P**ulse, **G**rimace, **A**ctivity and **R**espiration. There are two APGAR scores that are recorded, the first taken one minute following birth and the other five minutes later.

women's accusations that c-sections are undertaken due to lack of training as opposed to medical necessity, as will be discussed at length in later chapters. Other studies from Western nations also document significantly higher rates of operative deliveries¹⁰, prolonged second stage of labor, higher rates of post-partum hemorrhage, induction, and low amniotic fluid (Essen et al 2000, Small et al 2008, Vangen et al 2002).

There is only one U.S study yielding comprehensive quantitative data concerning Somali birth sequelae, which reveals similar sequelae to that determined by the European studies. It reports that Somali women in Washington State undergo c-section at a rate twice as high as their white and black American-born counterparts (Johnson et al 2005). Somali births are also associated with high rates of third and fourth degree tearing and a high rate of both low amniotic fluid and delivery post 42 weeks of gestation, both of which are significant indications for c-section (Johnson et al 2005).

Many of the stated adverse outcomes are intricately related and must be acknowledged as having a causal relationship; c-section rates do not stand alone but are rather directly affected by indications of fetal stress, low amniotic fluid, prolonged labor and failure of induction.

Inductions are associated with higher rates of c-section¹¹, as are the indications of low amniotic fluid and prolonged second stage of labor. It is crucial to acknowledge the role of providers "managing" Somali births in exacerbating, and at times bringing about various sequelae. Though the scar tissue of circumcisions allows for less elasticity, and thus higher risks for tearing and hemorrhage, it is important to note that the rate of painful third and fourth degree lacerations, which take a long time to heal, can be greatly minimized by timely de-fibulations (Herrel et al

¹⁰ This refers to birth with the use of vacuum or forceps.

¹¹ A recent study found a significant relationship between elective inductions and c-sections among women giving birth for the first time. In fact, induced births were twice as likely to end in a c-section (Maslow and Sweeny 2000). However, since many of the Somali women were induced after their due date, some of these induction were medically-mandated and not elective, and thus the results may not be wholly applicable.

2004)¹². A Swedish study interviewing midwives about their care of Somali patients revealed that when providers hesitated during labor, unsure of how to proceed with a de-fibulation, women experienced excessive tearing and bleeding (Widmark, Tishelman and Ahlberg 2002).

Another point of contention with the published statistics about obstetric sequelae stems from Scandinavian data asserting a prevalence of low APGAR scores among Somali newborns. There is some debate about the validity of these findings, which calls into question the ability of Nordic providers to correctly assess a newborn with a dark complexion (Essen 2000). This theory has not yet been proven, and is likely less relevant for the U.S, which has a more heterogeneous population than Norway and Sweden. However, questioning the validity of the APGAR scores serves as an important reminder: data gleaned from these studies cannot be taken as indisputable.

Prior to arriving in the West, the Somali women in the study had been surrounded only by circumcised women. Thus, many of the complications delineated by health care providers were normalized in Somali society. While infection and menstrual blockage were always understood as risks of the practice, the necessity for episiotomies during birth and the lessening of sensation during sexual interaction only became understood as problematic once the women encountered the negative biomedical discourses surrounding the care of circumcised women. Here, the term "second circumcision" comes once more into play. The stigma and preoccupation of Western providers with Somali women's circumcisions can be seen to negatively affect the care the women receive. As my thesis will explicate, many of the complications and risks associated with circumcision can be prevented almost entirely within the confines of biomedicine. The adverse outcomes that remain in U.S hospitals are in some ways constructed by the failure of biomedicine to adapt to the needs of the Somali population and do not

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¹² It is also true that de-fibulations also reduce the risk for prolonged second stage of labor (DeSilva 1989)

necessarily stem from "disfigured" genitalia. There must be an allowance for both the role of human error and the test of time to help differentiate between physiological and cultural elements resulting in adverse obstetric sequelae.

Robbed Sexualities? The myth of the de-sexualized woman

The debate concerning the sexuality of circumcised women is quite polemical. There is a plethora of published information concerning the negative effects of circumcision on sexuality, most of which makes sweeping claims about women's sexuality being "defective," "castrated" and "blinded" (Bell 2005, 130). However, as Obermeyer (2005) notes, most of the studies available are plagued by flawed design and analysis. Furthermore, they fail to address the complexity of measuring amorphous terms such as sexuality and pleasure. "The measures selected to represent sexual health all make assumptions about women's understandings and experiences, and also about the connection between sexual activity and sexual pleasure" (455). Instead of culturally driven categories, many of these studies are based on Westernized notions of sexuality, measurable terms which are wrongly assumed as unchanging cross-culturally (Catania et al 2007).

There are a few notable researchers, and many circumcised women, who passionately reject these generalizations about the de-sexualized nature of circumcised women. Catania et al's 2007 study of Somali immigrants in Florence concluded that "FGM/C does not necessarily have a negative effect on psychosexual life (fantasies, desire, pleasure, ability to experience orgasm)" (1673). A groundbreaking study of Sudanese women (the majority of whom were infibulated) revealed that 94 percent of them experienced sexual satisfaction and orgasm. These orgasms may be weaker, less frequent, and more difficult to elicit but they still happen (Lightfoot-Klein 1989).

While some of the women in the Columbus study experience reduced sexual pleasure and stimulation during sexual experiences, many other women describe happy sexual relationships, revealing that they do experience pleasure. A study of Somali women in Sweden reveals still more stories that shatter the myth of the de-sexualized woman portrayed in Western medical and public discourses. Here, the power of the "second circumcision," caused by the shame and public scorn attached to female genital cutting, is seen as a tool for "othering" women, depriving them of confidence in their sexual contentment. Indeed, women in both the Columbus and Swedish study discussed feeling stigmatized by public messages of their supposed loss of sexual pleasure. Moreover, many shared resentment of anti-FGC messages that create negative expectations of sexual experiences (Essen et al 2002).

Women in the Columbus study described initial intercourse as very painful, but most of them described pain lessening over time, especially after childbirth. Most women claimed to be fairly satisfied by husbands who know their pain and respect their needs. Furthermore, they spoke of experiencing pleasure: "we have feelings but not as much as other women," said one woman with a Pharonic circumcision. She went on to describe with some sadness that since coming to the U.S and learning about what uncircumcised women experience sexually, she is now somewhat disappointed. "Now that we know what missing, unhappy with practice," she said. Many of the women shared this viewpoint, revealing once more the way in which their concept of self and satisfaction with bodily experiences has shifted as a result of their move to the West. Previous studies of Somali and Sudanese women found similar states of unhappiness among women who gained new understandings about their lost levels of sensation. (Johnsdotter 2009, Lightfoot-Klein 1989). New revelations did not always bring disappointment. Depending on the circumcision, parts of the clitoris remain intact and are hidden under scar tissue. Women

may have the chance to experience pleasure by way of the clitoris after undergoing reconstructive surgeries and defibulation. One woman excitedly discussed her discovery of this possibility: "a woman could have sensation and woman don't know that...tell me where I can find it!" she exclaimed, bursting out in laughter.

The women in the Columbus study were quick to stress the intricate link between emotions and pleasure, stating empathically that, "it has to do with you[r] feelings for your husband, and your love, and the relationship. It's more than just what tissue was cut...the feelings are in your heart and in your body, and not just in your vulva." Bell (2005) made a similar claim in her discussion of the ethnocentrism with which the sexuality of circumcised women has been discussed: "sexual pleasure and desire are impossible to quantify and measure, and they are certainly not reducible to observable biological response" (139).

It is meaningful to note the tone with which the women responded to questions of sexuality and genital sensitivity. Many women stressed the culturally appropriate norms of public interactions between Somali partners. They took particular offense at the assumptions made by the mainstream American discourse surrounding the supposed lack of intimacy and affection in Somali marital relationships. Describing her happy marriage, one middle-aged woman said, "in America, they think we hate each other...We do what we want to do behind closed doors. When we are in public we don't kiss or show love...because it's shame".

Chapter 4: In Somali, c-section is a four-letter word: Somali perceptions, aversion and experiences with cesarean section in the West

C-sections refer to the medical procedure by which babies are delivered through a surgical incision to the lower abdomen. C-sections can be lifesaving in cases where vaginal birth would be dangerous for mother and child, either because there are signs of distress that necessitate a quick birth or in circumstances where vaginal birth is improbable. The American Congress of Obstetrics and Gynecologists (ACOG 2004) widely distributes a pamphlet informing women about c-sections. The pink pamphlet discusses the risks of c-section and includes the following reasons for the procedure: pregnancy with multiples, failure of labor to progress, concern for the baby, problems with the placenta, previous c-sections, breech presentation, large babies, and maternal infections. For complicated births, c-sections give women and babies a chance at survival. When c-sections are not medically mandated, however, the risks posed by the operation far outweigh the benefits. Though the ACOG pamphlet — and for that matter, many providers — gloss over the risks of c-section, they put women at risk for all the complications associated with any major invasive surgeries including infection, blood loss, clotting, and reaction to anesthesia (ACOG 2006). Unlike an appendectomy, however, c-sections also pose a second set of risks considered more personal and psychological. These include a greatly reduced rate of breastfeeding¹³ and a sense of personal failure¹⁴ by birthing women (Davis-Floyd 1992). Recovery time is an expected consequence of operative surgeries, but pregnant women are not sick, and unless the c-section is planned, women have neither

¹³ This is not only an emotional toll taken on the bonding between mother and child, but also a financial one: formula feeding is estimated to cost over 1000 dollars a year (Breastfeeding Coalition 2001).

¹⁴ For more information on the topic of empowerment and birth see Robbie Davis-Floyd's *Birth as an American Rite* of Passage (2002)

logistically nor mentally prepared for an extended period of recovery and abstinence from their regular day-to-day activities and responsibilities.

According to Taffel, Placek and Liss (1987), the optimal rate of c-sections should fall between five and 10 percent. Using WHO statistics they conclude that, "there is no justification to have a cesarean section rate higher than ten-to-fifteen percent". The U.S c-section rate has not corresponded with these recommendations since 1970 (Taffel, Placek and Liss 1987). In 2010, the CDC¹⁵ reported the current U.S c-section rate at 32 percent, having risen year by year with no signs of slowing (Menacker and Hamilton 2010). The general U.S population rate of c-section in the U.S is egregiously high; the rate in the Somali community is even larger. Many studies from the U.S and other Western nations corroborate these rates, and a large study spanning six receiving nations—Australia, Belgium, Canada, Norway and Sweden—found that in four out of the six nations, Somali women had a significantly higher rate of c-section than did native-born counterparts (Johnson et al 2005, Small et al 2008, Vangen et al 2000, Vangen et al 2002).

"The Streamline": Somali perspectives on c-section

Childbirth is like going in a tunnel and you never know whether you are coming out alive—(Somali woman in Vangen et al 2004, 33)

Women in Somalia have a one in 12 chance of dying in childbirth over the course of their lifetimes — a rate nearly a 100 times that of the United States and one of the highest rates of maternal mortality in the world (Unicef 2010c). As such, Somali women recognize childbirth as a time of great anticipation and joy but also as one of intense fear and vulnerability (Essen 2000).

¹⁵ Centers for Disease Control and Prevention

Traditional birth attendants oversee most births in Somalia, with 33 percent of births attended by professionally trained midwives and physicians (WHO 2006). The women in the Columbus study, in conjunction with their counterparts in previous qualitative studies, described births in Somalia as generally taking place either at home or in the birthing center of the village, often with the presence of women from the community. On the other hand, births in the refugee camps in Kenya were said to have taken place in field hospitals and were described by women as riddled with shortages of medical equipment and personnel. In both locations, access to emergency obstetric care was almost nonexistent, hindered by geographic distance, lack of infrastructure, and prohibitive monetary expense. "Some women if they don't have money have the child die inside of them," concluded one woman, matter-of-factly.

In cases where a decision was made to travel to the hospital for a c-section, outcomes were often adversely affected by the travel and time lapse between decision and arrival; frequent deficiencies in medical equipment and sterile conditions only exacerbated the risk of negative consequences. Death was a ubiquitous element of every mention of c-section among the women in the study. C-sections were considered a measure last of resort, taken only in the most dire of cases. Instead, women in rural Somalia experiencing complications during birth worked with the midwife and women from the community toward a vaginal birth, fully cognizant that without obstetric intervention, death was imminent.

As is to be expected, c-sections were regarded with fear and aversion, an adaptive reaction to learned realities (Vangen et al 2004). Indeed, these averse attitudes to c-section were one of the most saturated themes in the Columbus study and have been well documented by numerous other studies (Chalmers and Hashi 2000, Dundek 2006, Essen et al 2000, Lundberg and Gertzingher 2008, Vangen et al 2004). In the U.S, the experience of Somali women with c-

section has been drastically different. Nevertheless, the fear of c-section holds fast, informing the women's perceptions and reactions to experiences with birth in the Midwest. The following chapter details the women's perceptions of the causes of c-sections in the U.S, which they consider excessive, unnecessary, and highly problematic.

In many ways, the Somali women's intense aversion to c-section in the U.S is much more powerful than it had been in Somalia and Kenya. No longer a question of life and death, considerations to undergo a c-section are more complicated and more personal, hinging upon the power of the intervention to affect the quality of life of Somali women, in very tangible, crucial ways. "[C-section] is an injury. You face too many problems," said one woman, describing the c-sections her daughter experienced in the U.S after she herself had given birth vaginally to 12 children in Somalia. Another woman explicated: "it bothers those women who go through it. Some have their wound open, some can't have many kids or must space out births, and some have their wound bleeding and it won't close. They fear problems happening to their body."

Many of the Somali women correctly understand that c-sections effectively place a limit on the number of children a woman can safely bear. With each successive c-section, the risk for uterine rupture increases, posing a life-threatening risk for both mother and child (ACOG 2004). In Somalia, women traditionally have large families, giving birth to an average of 6.7 children nationally (WHO 2006). Highly religious, Somali women believe Allah determines the number of children they will bear, a mindset that influences the lack of interest in birth control and family planning. As a result, the Somali women in the Columbus study detailed aversion to c-sections and to the notion that a doctor-imposed intervention would supersede the God's decision for the number of children in a given family and the age differences between them. Asked to explain the Somali community's position towards c-section, one woman, who had not had any c-

sections, stated that, "it's like as if someone has died—comparable... because they are viewed as someone who can have children no more than two times." Women described their fear that Somali women in the U.S would be forced to have smaller families than they desired, not able to have large families like past generations had. Many other studies document similar viewpoints, including conspiratorial perceptions that U.S providers remove Somali women's uteri following c-section, thus terminating any possibility of successive pregnancies¹⁶ (Dundek 2006).

The women discussed the health risks involved in c-section, detailing their fear of it as a major invasive surgery requiring extended recovery time that prevents them from returning to their home responsibilities. As mentioned early, following childbirth women in Somalia are traditionally confined to their beds for a 40-day rest period during which women from the community tend to their needs, cook, clean, and take care of children while they regain their strength (Beine et al 1995, Lundberg and Gerezgiher 2008). The move to the U.S changed women's postpartum experiences dramatically. Women described with sadness the loss of this network of social support, describing their increased postpartum responsibilities as stressful and isolating (Berggren et al 2006, Lundberg and Gerezgiher 2008). As a result, they spoke with dread of c-section as limiting their ability to attend to their responsibilities: "by the time they come home they won't carry a lot and they want to do their house and stuff regularly and go shopping or do the regular scheduled things they used to do".

The aversion to c-section was unanimous among the women in the study, a discussion that was usually followed by women's reiteration of their intense desire for vaginal births. As opposed to the harmful, dangerous c-sections, vaginal births were described as natural, healthy and safe, not placing a limit on women's fertility and recovery. Thus, the women believed that

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¹⁶ Although the uterus removal theory is most likely due to medical misunderstandings, it highlights the mistrust the women feel towards the intentions of their providers.

all efforts should be made to achieve this desired birth, as had been done in Somalia and Kenya.

C-sections, the women concluded, should remain a measure of last resort.

Somali quest for vaginal births

The women's desires to avoid c-sections are not reflected by their birth experiences. A study of Somali women in Canada reports that though less than one percent of women in the study wanted a c-section, 50 percent experienced one (Chalmers and Hashi 2000). In fact, the women in the Columbus study delineated a trend of Somali women being c-sectioned in the U.S after successfully giving birth to multiple children vaginally in Somalia or in the Kenyan refugee camps. The women described these experiences incredulously: because women's physiology did not change after moving, why have Somali births become so "complicated" in the U.S?

Discussions about the rate of c-section in the Somali community largely centered upon a critique of Western biomedical practitioners, their standards of care, and the integrity of their intentions. Providers were criticized as being overly nonchalant in regard to c-section, authorizing c-sections before undertaking all measures to try to achieve a vaginal delivery. The women detailed a series of maneuvers used to rotate children or birth them breech, a long list of techniques used by providers in Somalia and Kenya to allow for vaginal birth regardless of the position of the fetus. One woman, a mother of four children, all of which she birthed vaginally, explained this determination for vaginal births:

Even if the child, for example, instead of sticking their head out sticks their hand out, they stick the hands back in and move the baby. Sometimes they [the baby] come around the wrong way...like the buttocks of the baby, and they [birth attendants] just adjust the baby... [American health care providers] don't wait...they just immediately do a surgery.

Another woman went further, giving detailed instructions on some of the techniques:

In Somalia when the woman is having a baby, always we try to deliver the natural way, even if there are complications. Even if the baby is upside down, they will deliver natural and if child brings one hand out first they will pull back the hand and deliver natural. If upside down, back first, will put hand and try to turn baby over, or put the mother upside down and shake the mother to turn the baby over; if limb comes out the midwife will pull it back in.

Disregarding the lack of options for non-vaginal births in rural settings, the women discussed Somali providers as sharing their determination for vaginal birth and being willing to go to extreme lengths to give women the births they so desired. In opposition, American providers were described as acting rashly, bringing about a multitude of c-sections that the Somali women declared excessive and preventable had providers employed similar strategies to those of Somali birth attendants.

The situation is much more complicated: American providers are no longer legally able to attend breech births, mandated by law to perform c-sections in cases of known breech presentation at term. Moreover, although versions¹⁷ are routinely employed in early stages of pregnancy in the U.S, they are considered incredibly painful and are rarely successful at-term. Thus, they are usually not attempted (ACOG 2007b). Hindered by law and fear of malpractice suits, American providers often avoid the techniques that act as lifesaving strategies in rural areas. However, as will be discussed in later chapters, communication between providers and Somali women is thwarted in many ways, and there is a clear lack of understanding among the Somali women concerning providers' decisions to avoid certain procedures.

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¹⁷ Versions refer to an obstetric technique used to rotate a fetus towards a head-down presentation in preparation for birth.

Lack of provider experience with circumcised women

The women in the Columbus study often attribute the high rate of c-sections in the Somali community to a perceived lack of provider experience with the perinatal care of circumcised women, believing that this inexperience affects providers' decisions to perform unnecessary c-sections instead of less invasive procedures like episiotomies. A young woman described the Somali conception that providers consider c-sections to be an easy, fail-safe way to avoid dealing with a woman's circumcision altogether:

Oh, they are only going to do the C-section to you. They are not going to give the other option just because they don't know anything about that area, it looks different, they are not used to it, so the doctor is not going to even make an effort, so they are just going to make you go through a C-section.

Others in the study agree and explained that Somali women seem to be fated for c-sections in the U.S merely because they are recognized as Somali, and thus circumcised. In this way, women describe how Somali women are automatically c-sectioned without the opportunity to give birth vaginally.

The significance of this perceived lack of choice is not to be neglected. It was raised by many of the women in the study who believe that because of the lack of ability and desire of provides to take the appropriate measures to allow for a vaginal birth, Somali women are not given the slightest chance to give birth in the manner they desire. Many women exasperatingly proclaimed that Somali women's health is being negatively affected by clinicians' lack of exposure to circumcised women: "this [de-fibulation] is not something he is trained in. Health care providers don't know it and is shocked when they see the [circumcision] because they are used to their open women." A Swedish study of Somali women documents similar experiences, whereby Somali women were shocked and scared upon realizing that their midwives did not

know how to properly handle their circumcisions (Berggren et al 2006). Furthermore, both in the Columbus study and the Swedish study, women described feeling that they have to fight to be heard, angered by the unwillingness of providers to confer with them about methods of episiotomy in cases where the Somali women feel that they have the upper hand in terms of knowledge and experience. "They don't ask. If they would have asked, we would have told them to cut up or to the sides, because they didn't ask and they saw the [circumcision], they just cut all over the place [bad episiotomy]". As a result of the stubbornness of providers and their ensuing faulty work, this woman continued, it is Somali women who suffer because, "the doctor is just thinking about opening her, he doesn't know the proper way…only wants to just open it for the baby, that's it."

"Let them wait": Somali perspectives on rushing

For unknown reasons, Somali pregnancies and births seem to take a long time. A study of Somali birth in Washington State found Somali women to have a nine-fold risk of giving birth past 42 weeks of gestation as compared with their American-born counterparts (Johnson 2005)¹⁸. Moreover, many obstetric studies have found Somalis to experience a prolonged second stage of labor — the time between full dilation of the cervix and birth of the child — at much higher rates than Americans and even non-Somali foreign-born women (DeSilva 1989, Essen and Wilken-Jensen 2003, Vangen et al 2000, Vangen et al 2002). The women in the Columbus study agree that vaginal births for circumcised women sometimes take longer than those of women who are

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¹⁸ Undoubtedly, this helps account for the higher rate of c-section induction in the Somali community. The same Washington state study found the rate of c-section among Somalis to be twice as high as that of the American-born counterparts.

not circumcised¹⁹. However, their conclusion about what should be done as a result of these longer pregnancies and births are drastically different from that of their providers. Whereas providers largely understand these longer gestations and second stages of labor to be indicative of problems, the women do not see these differences as inherently problematic and strongly oppose the formulaic move to intervene based on protocol. The women believe that if providers are cognizant of the longer length of Somali births, providers should give women more time to labor. "Sometimes vaginal births, when you are in labor, it takes a while. It takes some time and [health care providers] should be waiting. They don't wait for a long time, they just want to do a c-section on them."

Whereas biomedicine discusses the necessity of labor and birth to progress according to a distinct timeline universal for all births, the Somali women use terms that make clear their perspectives of the uniqueness of each birth and its timeframe. Thus, while ACOG defines strict hour-by-hour guidelines, the Somali women speak vaguely of "enough time" and "a few days" (Cheng and Caughey 2009). In this sense, the mindset of the Somali women corresponds with many of the critiques made by activists in the natural birth movement in terms of biomedicine's mechanization and medicalization of birth. This movement calls for a more personalized, birth-by-birth timeframe, arguing that women should not to be "punished" if their births "fall behind schedule".²⁰

The Somali women in the Columbus study believe that a pre-determined birth timeline is both foreign and unnatural. The women in the study discussed the framework of birth in Somalia and the refugee camps in Kenya as straightforward and unhurried: women went into labor and

¹⁹ It is crucial to note that episiotomies and de-fibulations greatly reduce the risk of prolonged labors (DeSilva 1989)

²⁰ For more information concerning the medicalization and mechanization of birth, see Emily Martin's *The Woman in the Body: A Cultural Analysis of Reproduction* (1987) and Robbie Davis-Floyd's *Birth as an American Rite of Passage* (1992).

eventually gave birth. As far as the women in the study are concerned, most c-sections in the Somali community are a result of providers rushing labor prematurely. "In Somalia, they don't rush to do a c-section. Only if a person has a major problem. If the girl doesn't immediately have the baby come out they tell her to go back home.... [American health care provides] don't wait...they just immediately do a surgery [c-section]."

Often, the women drew comparisons to their birth experiences in Somalia and the differences in the amount of time allotted to labor. An older woman, a mother of 12, angrily described her daughter's experience with c-section in the U.S, one that she attributed to excessive rushing by providers:

I swear by Allah, she [my daughter] went into labor and in my country, if a woman goes into labor tonight, that it's ok if she won't have baby until the next day, afternoon. In my country, few cesarean sections. We didn't know them. So, if she has a long labor, woman has a long labor, but if woman has long labor in America, they immediately do a c-section....Doctor is in a rush. They have to slow down, two, three, five, ten hours labor. Wait for them in labor. In America these days they don't let American women stay in labor. Let them wait with the pain, that's my advice.

God versus "The Machines"

It is critically important to note the role of faith and fatalism at play in these perspectives. Within these narratives is a tangible tension between God and technology. These two powers have prominence in Somali and biomedical cultures, respectively, and attempt to overthrow the other as dominant. From the perspective of many women, Allah — not the providers or their machines — can determine when a baby is ready to be born. Thus, the women greatly dislike feeling rushed by providers who bring about birth before Allah wills the birth to take place, and the authority with which providers present facts about the baby's condition as immutable

evidence for the necessity of a c-section²¹. "We say God will bring the children out, but here they say that the heart goes down in baby so we must perform a cesarean section."

In their arguments, a critical rift is revealed in terms of how Somali and American biomedical systems construct and understand medical knowledge and evidence. Part of the Somali mistrust of medical technology is mediated by a lack of understanding and exposure to this technology. As immigrants with a history of low-technology births, Somali women do not have the years of enculturation and exposure that many American women have to the biomedical process of birth. Whereas the Somali women describe feeling fear and mistrust with any type of intervention, most American women, ironically, feel anxious and fearful if these technologies are *not* used, having come to rely upon the data provided by these technologies as assurance that their birth is going well (Davis-Floyd 1992).

There is an important difference between reliance on God or technology as ultimate power and knowledge. Even if birth does not end with a healthy mother and child, a belief in God's will as immutable allows one to make sense of the experience under the framework of fatalism. The data provided by medical technology is not absolute: it is subject to human error and chance. The Somali women revel in stories that prove the incompetence of medical providers and their technologies, a triumph of God's superiority and the women's faith in Him. One woman spoke triumphantly about giving birth vaginally despite being told by providers that she must undergo a c-section due to the large size of her child. Doubting her providers' judgments, she merely changed providers and achieved the vaginal birth she believed God intended.

Restriction of movement

The Somali women detailed many techniques to promote vaginal births. Among these methods, movement during labor was one of the most central, a learned way for women to speed up labor and prevent a c-section. In Somalia and Kenya, movement was not only understood as beneficial, but enforced by health care providers. One woman explained that the belief in the necessity of movement was so great that, "if a woman is seen in bed, the doctor will argue with the woman... If you are in bed and have too much pain, they will have two people hold you up and walk you around. Baby come down. In Somalia, even if throwing up." Gravity was understood to be key to cervical dilation; a woman in labor was not to lie in bed, but rather walk around, moving to help ease her child out. One woman in her mid-fifties, a dynamic and expressive mother of 12, acted out the laboring scene during her interview to explain the necessity of movement. She stood up, leaned back holding her lower back indicating that she was (very) pregnant, and walked in circles around the room, repeating: "always walking, always walking". In fact, biomedical evidence supports the Somali women's claims about the power of gravity, which the lithotomy position²² effectively eliminates. A Cochrane review found that in comparison to births in the lithotomy position, upright and squatting birth positions allowed for a considerably faster second stage of labor, though interestingly no difference in rates of csection²³ (Rosser 2003).

In U.S delivery rooms, Somali women sometimes clash with providers when they attempt to get out of bed and walk around to speed up their births. Restricted by fetal heart monitors, intravenous drips, and electrical cords, the women described feeling trapped, powerless to

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²² that is, birthing lying on ones back.

²³ However, the Cochrane study examined the population at large, and since prolonged second stage of labor is a major indication for many c-sections in the Somali community, a study examining the use of alternative birthing positions for Somali women may yield different results.

prevent the c-sections that became necessary as a result of their prolonged labors and restricted movement: "in America, they put woman on the bed and they tie them up with cords...they are in bed with equipment, so the child doesn't come out... They end up getting cut." Women in the study lament the drastic difference in provider approaches to movement following their moves to the U.S. Whereas Somali providers forced women out of bed, American providers now mandate that they remain inert, or as one woman put it—"stuck in bed". The women propose instead that women should be allowed to walk around and not remain strapped to a bed, passively "waiting" for a c-section.

While it is true that constant fetal heart monitoring is necessary with the use of an epidural, Somali usage of anesthesia is much lower than the average population (Small et al 2008). Most women in the study declared their great aversion to epidurals. The women understand epidurals not only to numb pain that they endure with dignity — as opposed to painfearing American women who run from it — but also to cause enduring "crippling" back pain, as anecdotally experienced by many women in the community (Small et al 2008). Since the use of anesthesia by the Somali women is so low, one might expect that providers would be more apt to use periodic manual auscultations²⁴, which are just as effective in determining fetal heart rate and are in fact associated with lower rates of false indications of fetal distress than are electronic fetal monitors (Davis-Floyd 1992). There has been a gradual de-skilling within the arena of birth in U.S. and fetal heart monitoring is no exception. Put bluntly, electronic fetal heart monitors are easier for providers and hospitals to use but Somali women are restricted by cords, forced to lie on their backs, connected to machines whose evidence they do not necessarily trust.

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²⁴ This refers to listening for a fetus's heart rate with the use of external instruments such as a fetoscope or doppler device. This method can be easily performed in remote areas and outside medical settings (Gilles et al 1997).

A Question of Motives

[Providers] in America are making money. They just want to do surgery, c-sections all the time. They don't do that to their women. Only to us refugees- Somali woman in the Columbus study

The Somali women in the study are painfully aware that wearing their traditional Somali clothing sets them apart visually from other clients seeking prenatal care. They often discussed experiences with insensitive providers who they felt negatively judged and treated them based on their religion. The women feel that in the aftermath of 9/11, their traditional hijabs are sometimes seen as an indication of extreme Islam and terrorism and not a sign of modesty and religious faith. The women described a growing sense of unease with their experiences with providers, detailing experiences of overt, and more commonly, covert discrimination. Highly sensitive to their vulnerability as Muslim refugees, a few of the women link the high rates of c-section in the Somali community to discrimination by providers.

Monetary benefits are also central to the women's questioning of provider's motivations to provide c-sections. Many women claim that providers push for c-sections as a way to make more money at the expense of Somali women. A young woman who emigrated to the U.S in her teens and has since married and given birth explained that many Somali women believe that when providers tell patients that a c-section is medically necessary, they are actually doing so for the sake of money, and not to save lives. A survey of Somali health from Minneapolis recorded similar perceptions among Somali women in terms of claims of monetary motivations for c-sections. Interestingly, the study also reveals claims that providers were experimenting with c-sections on Somalis (Herrel et al 2004). These are powerful allegations. They carry with them the weight of a long history of hideous experimentation on black bodies, both through

colonialism in Africa and in the U.S. Though unsubstantiated by evidence, such claims must be taken seriously as powerful evidence of the fundamental lack of trust Somali women have in the basic motivations of their providers to "do no harm." This theme of mistrust will be explored in detail in later chapters, but it is important to highlight the many ways in which this basic mistrust in providers and the health care system shapes Somali decisions to take health into their own hands.

As a side note, though vehemently denied by most providers I have spoken to, hospitals, if not individual providers, do in fact make more money by providing c-sections than vaginal births through higher insurance claims and faster changeover of women (Childbirth Connection 2010). I do not claim that providers consciously opt for c-sections for monetary reasons, but I do believe that the infrastructure set up by the ever-increasing number of for-profit private hospitals sustains protocol and physical structures that make the decision to c-section conveniently effortless²⁵. A study by Burns et al (1995) reported that c-section rates "curiously" declined during nighttime and weekends to correspond with providers' desires to go home. Rather than indicated by medical necessity alone, the study revealed that providers' schedules, locations of training, and personal inclinations to c-section play a significant role in indicating for c-section. Likewise, two providers in the documentary *The Business of Being Born* (2008) explain the c-section spikes at four and ten p.m. as corresponding with providers' meal times and changes in shift.

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²⁵ During a discussion on November 6, 2008, Women's Studies professor Joanne Motino Bailey relayed a local example: according to her, the new University of Michigan Labor and Delivery unit has been built to sustain a fifty-percent c-section rate, with each delivery room purposefully designed to be "conveniently" located directly across the hall from an operating room.

Provider perspectives

The accusations made by the Somali women concerning providers and their misguided use of c-section is disconcerting. Even if the women's accusations were entirely fabricated, which unfortunately they are not, the fact that the women's mistrust in providers propels actions to take their healthcare into their own hands demands that the accusation—their roots and effects—be examined seriously. The Somali study does not include the voices of providers, but a sister study conducted by Jalana Lazar (2008) interviewed providers in the Columbus area about their experiences with Somali patients provides a critical angle of exploration onto the experiences of the Somali women.

Interestingly, many of the providers that Lazar interviewed are aware of the Somali perception of providers rushing to perform c-sections but refute the validity of the accusation entirely. In fact, these providers claim that Somali women do not have higher rates of c-section than the general population. Instead, they postulate that Somali women perceive the c-section rate to be exorbitant because c-sections so seldom happen in Somalia. One provider spoke about being hurt by the mistrust his patients have in his motives: "our sense is that they perceive we want to do c-sections because it is somehow faster, easier, or more financially rewarding for us, and that we don't want to wait for the vaginal delivery, we just want to push them to have a c-section...I don't feel this is accurate" (Lazar 2008, 17). While these providers acknowledge the role of c-section as limiting fertility and thus understand some of the Somali aversion to c-section, a great rift between providers and patients is clearly demarcated when providers go on to state that they can not understand their patients' choices to refuse c-sections that would save a healthy child in exchange for the possibility of having more children in the future. Providers

conclude that they attempt to respect their patients' wishes. Regardless of their intentions, patients still often detect the underlying sentiments of providers.

Only one provider in the Lazar study received training concerning the care of circumcised women, and despite the large number of Somali patients in the Columbus area, none of the hospitals where these providers worked provided any training or protocol. However, most of the providers stated they now feel adequately prepared for their interactions with Somali patients after on-the-job training. These confident voices from Columbus come in direct opposition to those of providers in other countries. In all the previous studies that I researched concerning provider perspectives on care for Somali patients, lack of knowledge and experience is one of the most dominant themes (Chalmers and Hashi 2000, Essen et al 2000, Herrel et al 2004, Tamaddon et al 2005, Vangen et al 2002, Vangen et al 2004). In fact, in studies from the United Kingdom and Sweden, providers go further, admitting that some of the adverse outcomes and experiences of Somali vaginal births are exacerbated by the fact that providers are unprepared and inexperienced with care of circumcised women (Straus, McEwen and Hussein 2009, Widmark, Tishelman and Ahlberg 2002). One Somali woman, discussing her experience with a midwife unfamiliar with de-fibulation stated angrily, "I told her, even if you've had a baby, you need an episiotomy, to be cut. It was my fourth child; I even wrote it down for her... She was afraid to cut a vein... I got a laceration" (Straus, McEwen and Hussein 2009).

As for the link between c-sections and providers' lack of experience, many of the studies confirm Somali women's accusations. Providers in studies from Britain, Sweden and Norway admit that c-sections are at times performed because they do not know how to manage the vaginal births of circumcised women (Essen et al 2000, Straus, McEwen and Hussein 2009, Vangen et al 2002, Vangen et al 2004).

With such a unified response from providers outside the U.S, the results from Columbus seem curiously optimistic. Perhaps providers in the U.S are less honest about their mistakes and shortcomings²⁶, and it also may be true that Somali women's perceptions are skewed by their experiences as refugees in a foreign medical system. However, when the voices of providers and their patients are compared, the flagrant differences between them necessitate further study and a refusal to "pick sides". As will be discussed in the next chapter, miscommunication plays a prominent role in maintaining the divide between these two divergent narratives of the same births.

²⁶ It is important to note that a report from Minneapolis suggests a possible link between c-sections and lack of adequate training but does not include interviews with providers (Herrel et al 2004).

Chapter 5: Breaking trust: relationships with providers

When you go to the doctor you are disrespected—Somali woman in the Columbus study

Most of the Somali women described uneasy experiences when seeking health care. Sometimes it is a side comment made by a nurse regarding the woman's successive pregnancies; other times, a stereotypical assumption that providers based their care upon, instead of asking the woman. When speaking about these experiences, the Somali women described feeling patronized and judged by medical staffers. These experiences made women anxious about being disrespected during doctor visits, and sometimes convinced them to put off seeking care all together (Berggren et al 2006). "A lot of people...they don't want to go to hospital because they feel like they are ashamed of themselves or they will make like, oh, that from another country, like they are less than them, and stuff. So I see a lot of people that rather stay home even though they have pain." When discussing the power of these negative interactions to influence women's behaviors surrounding childbirth, developing trust is a crucial element in bringing about better health outcomes for Somali women and their babies. The following chapter seeks to tease out some of the elements in the interactions between providers and patients that lead to the damaging of trust and the eventual decisions of women to act against providers, and not alongside them.

As discussed previously, some of the women attribute their c-sections to discrimination by providers, feeling that providers do not have their best interests in mind, and are thus willing to compromise care for the sake of speed and ease. Many women associated providers' reactions to traditional Somali Islamic dress to experiences of suboptimal care: "because of my veil. If I looked American they would have tried," said one woman in her mid-fifties. Even more disturbing is the real fear shared by a few of the women that providers might try to hurt them as a

result of hatred against Muslims in the wake of the 9/11 terrorist attacks: "before the country was okay, but after 9/11, the situation changed. Women are treated badly. Sometimes I fear going to the doctor because I fear they will do something to me." Much of this perception stems not from overt comments made by providers but from experiences of women feeling disrespected and judged as a result of provider's body language and reactions:

I feel that my culture and religion and dress bothers them. They don't say anything...but I can feel it. When I am taking my time to remove my layers of clothing for example the x-ray person looks annoyed. You can tell that my religion and faith is bothering them.

In studies of providers' experiences with Somali women, many providers acknowledged that they consciously work to try and hide their discontentment with certain aspects of patient's cultural, religious and reproductive choices. Despite their efforts to convey cultural sensitivity, patients still pick up on unspoken sentiments through providers' body language and attitudes. Providers from multiple studies admit to being aware of their shoddy efforts at concealment (Leval et al 2004, Widmark, Tishleman and Ahlberg 2002). One Swedish midwife said, "you're angry and your body shows it. And then you think 'no, I mustn't show anything', but your eyes and body language . . . that isn't anything we can decide to control" (Widmark, Tishleman and Ahlberg 2002, 118). These Swedish midwives describe feeling protective of the women, treating them with tenderness and displaying paternalistic identification with the women's "loss of sexuality" as a result of the circumcision. These emotions are reversed in terms of the laboring women's male partners, however, whom the midwives regard at the culprits of the "terrible state" of the women. So great is their anger, in fact, that some midwives went as far as comparing intercourse between Somali women and men to rape (Leval et al 2004).

It's difficult, because you are so angry. You get so . . . get so enraged at the whole situation, at the whole culture for something . . . a little primitive, sometimes it seems that I only feel upset. How the hell can they subject women to that, to this. . . . I

become so furious at men (midwife in, Leval et al 2004, 749).

In trying to be sensitive to Somali women whom they regard as helpless victims of a brutal culture, the midwives make many paternalistic and ethnocentric assumptions about the women's desires instead of discussing them with the women themselves (Carroll et al 2007a, Leval et al 2004, Vangen et al 2003, Vangen et al 2004, Widmark, Tishleman and Ahlmberg 2002). Moreover, Vangen et al (2004) noticed a trend whereby providers count on other medical personnel who interact with pregnant Somali women to bring up circumcision. By avoiding this topic, no one with medical authority over the imminent birth discusses options and expectations with the women prior to their labor. In a Canadian study by Chalmers and Hashi (2000), nearly 80 percent of women in the study recalled a complete lack of discussion with providers concerning their risks for c-section. By failing to provide the women with adequate education about their health statuses, providers strip their patients of decision-making power and prepare their patients for experiences marked by distrust and fear.

While the providers avoid bringing up obstetric and gynecological issues concerning the women's circumcisions, not wanting to be intrusive and insensitive, the Somali women in turn are confused when it is not. Women reiterated in many instances that they indeed want to discuss their circumcisions and what they should expect from childbirth, and hope that providers will introduce the subject. On their own account, Somali women in multiple studies describe being embarrassed to raise the topic themselves, fearing stigmatization by providers (Vangen et al 2004, Berggren et al 2006).

Many of the women feel that providers are not listening to them. They recall having to repeat themselves over and over again, fighting to be heard. "[Doctors] do not give you full attention when they take care of you, won't look at your face." The women describe becoming

distrustful of providers after such experiences. "I went to the doctor twice...but they didn't even look at me. They just wrote me some pills...you lose your trust with doctors when you don't get treated properly." Providers claim that they are aware of these sentiments among their patients but are unsure of the root causes of their patients' misgivings: "I think it's mistrust. I think they think we're trying to hurt them. I don't know why. I wish it wasn't there. It's very common and I don't understand it" (Lazar 2008, 21).

The Somali women *do* understand the reasons for their mistrust. Women in multiple studies detail experiences with providers who made overtly judgmental comments to women about their decisions to have large families with little spacing between each child. In one Canadian study, 90 percent of women recalled negative remarks made by providers (Chalmers and Hashi 2000). These off-hand comments are hurtful to the women, and they resent the patronizing tones providers take with them (Berggren et al 2006, Davies and Bath 2002, Straus, McEwen and Hussein 2009). Furthermore, many of the women feel that providers do not understand or respect their sensitivity about certain topics including privacy during labor.

When in pain, most of the women agree to be seen by male providers but almost exclusively prefer female providers. They value their privacy and ask that no unnecessary personnel be present during their labors. These requests are not only occasionally ignored, but also flagrantly disregarded. "I was in the hospital and refuse anyone to come in except the midwife, because I was in labor. After I gave birth, a friend said, see you were refusing men to come in, but look there were eight men and three women." Many of the women personally experienced being put on display by providers. One woman in her late twenties described an experience she had soon after coming to the U.S, in which she directly addressed the issues of disempowerment that may arise is such situations. When the woman sought care, her provider

called medical students into the room without the woman's permission to have them look at her circumcision:

Before that time I didn't speak good English...so they kept saying...oh look, what she's gone through, it's from another country...back then if I have voice or if I like have better English or better understanding, I was new to the country, so if I knew what I know today, I would have do something about it.

Many of the women spoke about feeling "othered" by such experiences, feeling like a source of amusement for curious medical personnel because of their "exotic" circumcisions (Berggren et al 2006). There is an astounding lack of sensitivity and advocacy for the women in these narratives. Providers are seen to almost use the barriers of communication to their advantage, superseding women's desires in ways that directly impact their involvement in their own care and their perceptions of future medical care. Since women rely so greatly on word-of-mouth information within their social networks, these negative experiences accumulate and help shape the weariness of women as a whole, regardless of their own experiences within the health care system. One woman in the Columbus study explained:

They have cultural scare problem, you know, they just think mistreated or, you know, disrespected because they've seen it, it happened to them already, so they think it's going to happen again, just have the scare problem.

Chapter 6: Complicated communications

(Mis)translation

Good communication between patient and provider, one that allows for open dialogue, is the factor influencing trust and satisfaction with healthcare experiences, not to mention vital components of treatment such as informed consent and decision-making (Davies and Bath 2002). Miscommunication, on the other hand, can lead not only to mistrust and misunderstanding, but also to faulty diagnosis and treatment. The communication barrier between Somali patients and their providers is both linguistic and cultural, and the use translators can at times backfire and serve to exacerbate misunderstandings between provider and patient. These are not issues that are unique to the Somali community; they are common elements in the experiences of many immigrant groups seeking care in Western hospitals, so much so that Norway now considers communication barriers to be a risk factor for adverse birth outcomes (Vangen et al 2002). However, there are particular cultural nuances in the Somali experience, as will be explored in the following chapter, that make translation and communication barriers particularly difficult to overcome.

Many hospitals serving a large Somali population have hired Somali translators, or at least make use of over-the-phone translation services. Despite these provisions and their ability to help in patient-doctor interactions, the Columbus-based Somali women's narratives include an abundance of issues regarding the quality and validity of translation services, ones that negatively affect their experiences and perceptions of care. The women in the study stressed an overall dissatisfaction with translation services, concluding that hospital-provided translators cannot be trusted to translate appropriately.

To begin with, despite greater access to hospital translators, many of the women still encounter healthcare situations in which translators are either unavailable or denied to them. Traditionally, Somali women are expected to remain closer to home than their husbands, caring for children and the household while the men seek work and interact in public arenas. While economic necessity and acculturation have allowed some women to gain access to English-speaking environments through the pursuit of higher education and employment, these traditional gendered spheres are still largely maintained, particularly for those women who emigrated at a later age. Regardless of time spent in the U.S, the overwhelming majority of women in the study feel that they do not have adequate English language skills, and consider themselves unprepared for interactions with providers without translation. This is particularly true in terms of medical procedures and terminology; the Somali women fear that they would not be able to accurately discuss issues with providers or understand the intricacies of what they were being told. Somalis often use figurative terms to describe physical or emotional states. Thus, a Somali patient may describe terrible back pain as 100 horses stampeding on their back. The women rely on translators to convey cultural meanings and to explain medical procedures and conditions with which the Somali women have little experience and clearly understand their need for translation to facilitate appropriate care. When translators fail to convey cultural meaning and merely translate word-for-word, the gap in understanding between patient and provider persists, leaving both provider and patient confused. One woman stated that, "I cannot speak the language and sometimes I do not have a translator. The biggest problem is when you don't get an interpreter, so can't tell doctor how you really feel.... If you have an interpreter, the interpreter will explain what you feel and you will be prescribed the right medicine and you will feel better."

Some women spoke of the practice of providers denying patients translation services on the grounds that their English is "good enough"—a flagrant disregard of nationwide translation policies. Women describe coping with such experiences by asking providers to repeat themselves, hoping that they understand *enough*. Many other women however, detailed their practice of bringing ad-hoc translators with them—usually a family member—both as back up and verification that hospital translators are translating accurately. One woman recalled that during a previous pregnancy she was refused a translator when she sought care at a prenatal clinic. The first thing she was told as she entered the clinic was, "our doctor's office won't provide interpreters, and if you don't speak English very well, then we will not see you.'" The woman returned later with an English-speaking family member.

Since Somali men tend to learn more English as a result of their exposure to non-Somali environments, the vast majority of translators—both ad-hoc and hospital-provided—are men. This becomes an issue when a man is asked to translate in cases pertaining to women's health, as happened to the pregnant woman at the prenatal clinic. When she requested that the translator leave the room for the ultrasound, her request was denied by the physician. Here, the communication barrier reaches beyond language itself, clearly marking a miscommunication in terms of the values and priorities of the patient that could have been alleviated with the use of a competent culturally sensitive translator. Within a clinic setting that can already be uncomfortable and distressing, these kinds of culturally insensitive interactions between providers and patients lead to an exacerbation of feelings of disempowerment.

Though ad-hoc translators lack formal medical translation training, they are still invaluable assets to women, sharing the burden of translation and thus allowing women to focus more on their health than on making sense of words. However, there are some significant issues that come

up with the use of relatives and friends as translators. Some interviews with providers revealed concern that women's wishes are no longer communicated once male partners begin translating. Aware of the gender power-dynamics at hand, providers felt that women sometimes hand over decision-making about their own care (Lazar 2008, Wiklund et al 2004).

Because of the relationship between women and their ad-hoc translators, some women describe feeling uncomfortable in situations that necessitate their choice between privacy and translation. The women detailed great unease with needing male translators to be part of discussions of utmost sensitivity, particularly those surrounding sexuality and their circumcision, which, in the case of obstetric and gynecological care, are unavoidable. Two young women, discussing their aversion to male translators, illuminated the importance for Somali women of keeping certain subjects quiet, and not sharing them with male translators: "I think when the trouble comes is when you have a translator and it is kind of hard for you to tell them everything.... Especially if they are male. It is very collective, keep it in the family, you know, hush, hush...don't talk about it." Even when hospital translators are used, due to the close-knit structure of the Somali community in Columbus, hospital translators often have some relation to the women, leading the women to fear that these translators might spread personal information about them.

Despite the issues with maintaining privacy that arise with the use of ad-hoc translators, many of the women prefer having them in the room with them as a guard against hospital-provided translator's incompetence or purposeful mistranslation. Many of the women spoke of translators who lack adequate language skills, mistranslating or failing to explain medical terms. One woman described her infuriating experience with an incompetent translator:

I tell them something in one way, and they go and they just mix up the English and the Somali, and they tell them something completely different from what

symptoms I have....Some of these people, they barely speak English. I speak better English than the interpreters.

For many women, the possible outcome of mistranslation is associated with a real fear connected to nightmarish tales of translation-gone-wrong that are rampant in the Somali community. One woman, seeming to revel in the storytelling, gave a specific example:

Some interpreters are bad. There was one time that a woman had her child get a diaper rash- they called an interpreter to translate. The woman who had the child was straight from the bush, lacked any knowledge of anything- just new. The interpreter instead of explaining the infection and diaper rash the child had told the doctors to castrate the boy... Now look that lady's baby is neither man or woman.

There are many such colorful stories told by the women, but at a less extreme level many women also speak of feeling uncertain that they are being translated accurately: "I tell the interpreter my problems, but I don't know if the interpreter is passing on what I tell them."

Besides mistranslation as a result of incompetence, the women also described experiences with deliberate mistranslation by male translators who look down upon the women. "When interpreters see you as uneducated," said one woman, "they try to take advantage of you and try to show off and act superior... I don't trust them, especially I don't want male interpreters....they like to show off." Male translators at times feel empowered to answer instead of a woman, making clear to her, if not to the provider, their influence in the decision-making. In some extreme cases, women even recalled being directly told by translators to "shut up": "when a women is having the baby and needs a translator she might tell the translator what she wants, but instead of the translator telling the doctor what she wants he tells the patient that you can not have it, not giving you a choice." Many of these translators are young, American-raised Somali men, and the women spoke about feeling that these men neither understand their

problems as women nor are empathetic to the women's sensitivity when discussing private matters.

Lastly, and of utmost importance, the majority of these patient-translator interactions are hidden from providers who remain oblivious to the power structures and social dynamics directing their experience with patients. Some providers, however, are aware of some of the problems with translators, expressing concerning about the quality and veracity of translation (Lazar 2008, Carroll et al 2007b). As one provider put it:

What [translators] need to do is to tell the patient what I tell them and I know they don't, they modify it, because I've had others chime in and say 'that's not what he said' so I'm suspicious that it's one of the problems we have in communicating. (Lazar 2008, 13)

Despite the fact that some providers are conscious of these issues, they remain dependent on translators, regardless of their incompetence, to communicate with patients. Considering the vital role that communication has for building trust and the variety of ways in which miscommunication is perpetuated between Somali patients and provides, it becomes clear how even the most well-meaning of provider intentions can be misconstrued, mistrust intensified.

Pathways to knowing

I don't know how to read. [Doctors] just say sign, sign...I refused to sign as asked them to read it to me – Somali woman in the Columbus study

The vast majority of women in the Columbus study are illiterate in both English and Somali. In fact, emphasis on written Somali is minimal, as the Somali language was only written down in the 1970s following a long history of oral tradition as the main route of communication and sharing of knowledge (Olden 1991). As such, when the Somali women are handed consent

forms, either in English or Somali—though they were rarely in Somali—the women feel discouraged, and at times refuse to sign altogether. Most of the women cannot read the pamphlets, but even if they could, they prefer to *hear* them (Straus, McEwen and Hussein 2009). Biomedicine relies heavily on written material to transmit information, whereas for the Somali women word-of-mouth is of utmost importance. Miscommunication between providers and patients is thus mediated by a cultural gap in modes of transmitting information (Olden 1991, Straus, McEwen and Hussein 2009). Here the role of translators is essential in facilitating informed consent and patient education, as they are able to verbally explain the procedures and terminology written on consent forms and information pamphlets. A Norwegian study pinpointed the difficulties with written material: "while [Somali women] received written information, they did not read it. Those who had read the information, however, found it difficult to understand and could not relate it to their own situation" (Vangen et al 2004, 33). In this case, the route of transmission of critical information about fetal heart monitoring failed to promote more trust and confidence among Somali women. This well-meaning attempt to prevent resistance to life-saving interventions through education backfired; the women felt even more confused and fearful about the procedures (Vangen et al 2004).

Many of the attempts to help promote trust in providers through education have failed to acknowledge the enormous role of oral informal exchanges within the community, which many women use as their main source of reliable information (Davies and Bath 2002). While providers are considered a major resource as well, the pervasive lack of trust among the women in their providers and their motivations, as highlighted in the previous chapter, prevents some women from fully trusting providers' competence, motivation, and reliability. Moreover, some women are uncomfortable with the judgment they feel providers make about their reproductive choices

and culture. The trust necessary to allow the women to feel safe asking sensitive questions is noticeably absent.

Obtaining information informally through word-of-mouth, however, is a much more convenient and safe method of getting hold of critical information about childbirth in the U.S. In the comfort and privacy of their community, confident in their ability to understand the information relayed, women seek information from their female counterparts concerning all matters of life. Women not only share experiences and lessons learned from their interactions with the health care system, but also provide advice and a strong network of support (Davies and Bath 2002). Here, the Somali tradition of storytelling is seen to serve both for and against the interest of the women. Community conclusions about the health care system come through clearly in an examination of the many stories told by the women during their interviews. These stories highlight the deep-seeded distrust of the Somali community in biomedicine and its practitioners, serving to substantiate women's fears of interventions and childbirth. The moral of many of the stories is the same, the plot lines follow a similar trajectory: perfectly healthy Somalis go to routine check-ups and end up dying as a result of doctors performing unnecessary procedures on them. Often, these stories are told in a half-joking manner, containing blatant exaggeration meant to amuse:

If you tell [doctors] I have a headache, they are going to have surgery on you in ten different places. There is a guy that he had his entire half of his skull was taken off and they put something plastic on there and told him he can't go out in the sun or else it will melt!

Other stories are more somber, centering on the women's experiences as voyeuristic interests for medical personnel due to their "exotic" circumcision. These stories bring to light the invasion of privacy that many women experience in the health care setting and also the pervasive sense of disempowerment in the community:

I also heard in Ohio they took a picture of this girl one girl's circumcision. Even when she was in labor. Rather than helping her they were taking pictures of her circumcision. Because this was something new and it surprised them.

There are many stories that denote a Somali impression of being medically experimented on or taken advantage of by American providers. One woman stated: "they test us. We are like guinea pigs, basically...This is [why] I am afraid of all hospitals." The deeply ingrained fear of c-sections and birth in U.S hospitals, as expressed by so many women in the Columbus study, seems to be validated and reinforced by the community's shared perception of providers' immoral motivations, as transmitted by storytelling and social exchanges.

Perhaps these stories serve as a coping mechanism and emotional outlet for Somali women and the disempowerment they experience. These stories, used in the U.S to facilitate knowledge despite the many barriers posed in interactions with health care providers, are also a continuation of a long tradition of oral transmission and storytelling, with a uniquely Somali flair. For the most part, the women seem to clearly enjoy the process of re-telling these wellknown stories that have become part of the shared community memory and knowledge, reestablishing community bonds through a perceived common experience. While some of the stories certainly contain grains of truth, much of the extreme exaggeration is likely due to misunderstanding. Unfortunately, these stories also serve to reinforce miscommunication and misperceptions concerning interactions and realities in the medical arena. The story about providers removing Somali uterus in order to give them to white women may have in reality been a case of medically-necessary hysterectomies the reasons for which the Somali patients did not fully comprehend. However, with the absence of "truth" about these stories, what remains is an overwhelming community force propelling women towards distrust and fear, and as shall be explored in the following chapters, shaping the women's strategies to avoid c-section.

Lack of knowledge about the health care system

Due to a lack of access to culturally appropriate forms of information and the issues with translation and communication that were highlighted in the previous chapter, many of the Somali women remain unclear about the benefits of certain medical procedures and technologies, considering them dangerous and error-prone. A study of Somali women receiving care in Britain revealed large gaps in the women's knowledge about accessing medical care as well as an overall unfamiliarity with the intricacies of the healthcare system and the procedures and guidelines within it (Davies and Bath 2002). This lack of knowledge about the healthcare system mediates the experiences of disempowerment described by some of the women in the Columbus study.

In regard to vaginal exams during obstetric and gynecological consultations, one woman asserted that, "I don't like the invasiveness of their examination where they put their finger in vaginal area and private areas." In fact, quite a few women mentioned their dislike of vaginal exams, describing them as intrusive and hurting. Vaginal exams can be uncomfortable and even painful, particularly for circumcised women, and many providers said that they try to be especially gentle when performing such examinations (Widmark, Tishelman and Ahlberg 2002). However, vaginal exams are an essential component of biomedical obstetric and gynecological care, a routine procedure that allows multiple assessments to be made about a woman's wellbeing. In Somalia and Kenya, where preventative and prenatal care is minimal, women described undressing only at the time of birth (Widmark, Tishelman and Ahlberg 2002). The notion of exposing oneself to a manual examination is jarring for many of the women, at times a deterrent to seeking care.

In another instance, a woman with a history of two previous c-sections became furious when she was told to prepare for a c-section for her third birth after becoming pregnant less than two years after her last c-section. Not fully comprehending the heightened risk of attempting a VBAC²⁷ after two c-sections without a full recovery from the last birth, the woman refused the c-section and was enraged that she was not being given a chance to birth vaginally. Both women did not understand the medical protocol behind the decisions of their providers and their experiences with them centered upon their belief that providers forced procedures upon the women unnecessarily. Here, communication and education could help foster understanding and trust among patients in the care that providers give them.

In a case documented by Vangen et al (2004), a woman whose fetus was showing signs of distress as indicated by a fetal heart monitor remained unconvinced that an emergency c-section was indeed necessary. The woman described feeling confused by the monitor, unable to make sense of the "evidence" on the screen being used to persuade her. Even though her doctor declared the fetus to be in danger, she was not sure. This tension can be seen throughout many of the Somali women's narratives about doubting the medical necessity of their c-section. The lack of understanding about the need of employing particular techniques is further hindered by a lack of knowledge about the ways in which providers use technology to ground medical decisions.

Whereas Western biomedicine has been de-skilled in many ways, with providers relying on a slew of technological tools to provide data concerning the wellbeing of a patient, much of the Somali experience with healthcare in Africa was through the use of traditional healers and manual examinations. Having lacked exposure to ultrasounds and fetal heart monitors, the women were incredulous that technology might be able to accurately provide information about

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²⁷ Vaginal Birth After C-section.

their internal physical condition. The women are reluctant to put their faith in machines and providers, feeding a growing tension between providers and women.

In a telephone conversation with Dr. Crista Johnson on November 12, 2009, she described a case of a laboring Somali woman who refused to accept a fetus's demise. Dr. Johnson attempted to persuade the laboring woman of the accuracy of the fetal heart monitor's ability to convey the wellbeing of the fetus, which at the time indicated a still line—no heartbeat. The woman and her family refused to accept this news. Instead, the woman insisted that she still felt movement, declaring that the monitor must have been erroneous. "But I can feel it," the woman kept repeating, her entire family joining to help persuade Dr. Johnson that the fetus was still alive. When the stillborn infant was delivered, both mother and provider were devastated. Dr. Johnson had hoped to help ease the pain of the loss. The refusal of the family to accept the news was heartbreaking.

At the most fundamental level, this is a tension between two ways of constructing knowledge with the use of particular evidence. This lack of trust in technology is a rejection of the medicalization of bodies that places the conclusions of machines over women's own bodily experiences. In the woman's rejection of the fetal heart monitor and the countless other examples framing the Somali women's distrust of machine-mediated evidence, there is also an affirmation of the power of intuition and bodily experience. As argued vehemently in regard to the theory of authoritative power²⁸, biomedicine fails many women through its inherent disregard of women's own knowledge about their body (Davis-Floyd 1994). As was seen regarding modes of defibulation and movement during labor, the Somali women brought into the medical arena their own time-tested methods for bringing about vaginal births; techniques they trusted because they

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²⁸ For more information, see Brigitte Jordan's *Birth in four Cultures: A Cross-cultural Investigation of Childbirth in Yucatan, Holland, Sweden, and the United States* (1993).

worked for generations. However, within the biomedical arena, there are distinct hierarchies of power, and the Somali's experience-based knowledge is at times disregarded, superceded by powerful machines and overconfident providers. This is not to say that the fetal heart monitors are always erroneous, or that providers should opt to ignore the significant benefits provided by modern biomedical technology. However, the manner in which many providers disregard the knowledge and experience of the women results in their feeling disrespected and disempowered.

Chapter 7: Defiant women: Somali mechanisms of action to prevent c-section

In many ways, Somali women exemplify the characteristics of the ideal patient: they are engaged, motivated, willing to do all it takes to bring about their wellbeing. They are known as outspoken patients, passionate about their beliefs and health. "Somali women are not passive," recalled Nicole Warren, a CNM who has worked with Somalis in Chicago, during a conversation on May 17, 2009. There is only one problem: providers and Somali women do not agree on the definition of a successful birth, or on the measures that must be taken in order to achieve one. Here is a lack of shared meaning; whereas providers conceive of c-sections resulting in a live newborn to be a healthy birth, many of the Somali women regarded them as disastrous. Some compared them to a death sentence. As a result of previous experiences and perceptions of c-section, Somali women have become determined to achieve a healthy birth under their definition, by doing all they can to guarantee a vaginal birth. As will be explored in the following chapter, these actions to regain control over their birth experiences often take the Somali women out from under the reach of providers, technologies and medical authoritative knowledge.

In discussing why some women question medical authority, rejecting the authoritative knowledge of providers, it is important to explore the ways in which most American women do not. Jordan and Irwin (1987) wrote: "most women willingly, gratefully, and deferentially accept medical intervention in this process-certainly in the case of cesarean section. ... Women make sense of the procedure as something that rescues them and their babies from disaster" (320). Since the Somali women highly distrust the motivations of providers and the necessity of c-sections, they are unable to accept their loss of control over the birthing experience by making sense of it as ultimately beneficial. Thus, patient-provider relationships of trust and dialogue give way to distrust and fear (Hernandez 2007). Instead of partners in health, some Somali women conceive

of providers as obstacles to wellbeing. While previous chapters have discussed the lack of Somali knowledge about the healthcare system, their various modes of action around providers and medical protocol reveal an intricate understanding that allows successful circumnavigation.

The Somali women are fully cognizant of their vulnerability within the medical arena, taking an active role to bring about their own wellbeing by maintaining the sphere of control over their bodies, making decisions to ensure vaginal birth by reclaiming their experiences. Within the labor and delivery unit, the authoritative knowledge of providers and technology is given precedence over the women's, understood as more "accurate", "scientific", objective" (Davis-Floyd 1994). The women's own desires and perceptions are otherwise ignored, disregarded and subdued, both physically and through medical rhetoric. By remaining outside the health arena for as long as possible, women act independently, but in culturally defined and accepted ways, to resist and reject the authoritative knowledge of providers and the disempowerment they feel as a result of their encounters with it. Though working independently of providers, the social networks of support in the Somali community create, support and uphold these behaviors in very particular, culturally appropriate ways. The experience of disempowerment is communal, the actions to resist it are as well. Away from providers, surrounded by women who share their perceptions and desires, Somali women maintain their own authoritative knowledge, putting into practice traditional methods of birthing in an environment in which their expertise over their own bodies was the one that counts.

Some actions the Somali women take are benign, and not unlike the decisions non-Somali women make in regard to the choice of a provider who shares the woman's intentions and approach to birth. Midwives experience lower rates of interventions than do obstetricians, and the Somali women's active decision to work with midwives as a way to reduce the risk of csection is not unique to them. Other Somali birth mechanisms to prevent c-section are far more drastic, harder for providers to grasp and respect. Non-Somali women, particularly those from other vulnerable social groups, have been known to refuse c-sections²⁹, but it is the saturation of refusal in the Somali community which has prepared some providers to expect refusal from *all* Somali patients (Jordan and Irwin 1987, Vangen 2004). Not always as dramatic as c-section refusal, the Somali actions are nevertheless a reaction against their vulnerability in the medical arena, a way to control the uncontrollable³⁰—not just birth, but providers themselves.

Reduction of nutritional intake

Among the strategies of c-section prevention documented by previous research, conscious reduction of nutritional intake is the most prevailing. Believing that smaller fetuses reduce a woman's risk for c-section, many Somali women intentionally begin eating less during pregnancy (Beine et al 1995, Calder, Brown and Rae 1993, Herrel et al 2004, Essen et al 2000, Lundberg and Gerezgiher 2008). There are a few women in the Columbus study that made similar comments, describing women who upon reaching six months of pregnancy decrease their fat and vitamin intake, hoping that a smaller child will ease a vaginal birth. For the most part, however, when the women in the study were directly asked about their dietary habits during pregnancy, they did not discuss the strategy of reducing caloric intake. This discrepancy in findings between the Columbus study and previous research is perplexing, but the fact that most of the women in the study detail healthy diets they maintain throughout pregnancy is encouraging.

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²⁹ For more information, see the interesting study by Jordan and Irwin (1987).

³⁰ See Davis-Floyd (1994) for discussion about women's desires for control during childbirth.

Three times a charm? changing providers

Many of the Somali women in the Columbus study women attribute c-sections to the incompetence of individual providers. As such, women do not believe recommendations given by providers to hold fast. When they were told in one hospital to expect a c-section, many women opted for a second or third opinion, changing providers until one gave them a different verdict. An Australian study by Hernandez (2007) reports similar trends. In some cases in Columbus, these decisions to change providers allowed women to give birth vaginally, becoming success stories in the Somali community. "Once I went to [1st hospital] and they said I need a csection because there was something wrong with my baby, then I went to [second hospital] and they said there was nothing wrong with my baby." The woman went on to give birth naturally, feeling triumphant that her judgment allowed her to prevent a c-section she had been told was unavoidable. Moreover, this decision to change providers reflects the women's belief in the lack of accuracy of biomedicine. When a woman told that she must undergo a c-section gives birth vaginally, she and her entire community feels vindicated in their efforts to get a second opinion and not take the word on any singular provider as absolute. That certainty, the women made sure to reiterate in the Columbus study is a trait unique only to Allah: "doctors don't have power. Only god knows the predestination." When providers told women that their only option for safe birth was a c-section, they decided not to rush to a decision but instead find ways to give themselves more of a chance for vaginal birth.

Midwives, the women quickly discovered, are a godsend. Less apt to perform interventions, midwives are understood to be strongly motivated to help Somali women give birth vaginally. Moreover, since the women realize that midwives cannot legally perform c-sections, many inaccurately concluded that with a midwife as provider, a vaginal birth is

guaranteed. Stories of women who gave birth vaginally with midwives only helped stoke the fire. One woman with a history of c-sections described a friend's four successful vaginal births, which both she and her friend attributed to the use of a midwife. In her hopeful attitude it was clear that the woman did not understand that midwives may only take on low-risk cases and that in cases of emergency, c-sections will still be provided, just not at the hands of the midwife.

Avoidance of prenatal care

Most of us don't go to the doctor until we are six months...because they will do invasive finger exam and have medical students...they don't do what you want, what you need—Somali woman in the Columbus study

Prenatal care was a concept considerably foreign to most of the women in the study before their arrival to the U.S. Back in Africa, some affluent women were seen by providers and given medication and vaccinations during pregnancy (Carroll et al 2007b, Upvall, Mohammed and Dodge 2009). The vast majority of women, however, report minimal prenatal care: "no money, no doctor," said one woman, succinctly summing up the Somali experience with preventative care. The women's attitude about prenatal care in the West is one that reveals a gradual acceptance of the concept of preventative care in general, one gained through exposure to biomedical concepts of health promotion. Many women report attending prenatal appointments regularly, and in fact, a few women admitted that prenatal examinations are the only form of preventive care they seek, revealing their understanding of the importance of the process. This is not true uniformly: a few women described delaying prenatal care because of their dislike of vaginal examinations and their fear that providers would perform unnecessary tests on them (Hernandez 2007, Narruhn 2008, Lundberg and Gerezgiher 2008, Upvall, Mohammed and Dodge 2009). Other women avoid prenatal exams altogether (Essen et al 2000,

Herrel et al 2004). A Canadian study by Chalmers and Hashi (2000) reports that on average Somali women wait until their 20th week of pregnancy to seek care, mostly as a result of fear. Meanwhile, ACOG recommends that women begin attending prenatal visits as soon as their pregnancy is confirmed (ACOG 2007a). When the women do attend prenatal examinations, Essen et al (2002) report that many refuse to undergo ultrasounds and purposefully fail to report lack of fetal movement, to the chagrin of providers. Many providers feel that the decreased interaction during the ante-natal period leads to a lack of establishment of rapport between providers and patients that contributes to mistrust and higher risks of adverse outcomes (Essen et al 2002, Herrel et al 2004).

Delaying arrival at the hospital

The women in the study described the strategy of c-section prevention through a delay of arrival to the hospital. "Most [American] women willingly submit themselves to the authority of the medical view... they manage to experience the techniques and procedures as reassuring and the delegation of authority to physicians as functioning in their own...best interests" (Jordan and Irwin 1989, 20). Not so for the Somali women. Entering the hospital constitutes a reluctant abdication of power into the hands of providers whose decision- making the women do not necessarily trust. Within hospital limits, the women feel that they are not given choices about their own care, treated with disrespect and largely ignored. The women react to an adage they are convinced is true: if you go to the hospital, you will get a c-section. Thus, they prefer to spend more time within the safe confines of their homes, waiting until the very last moment before heading to the hospital. As one middle-aged woman put it, "they don't even go. Their fear is so

great their child during labor is almost injured or they even give birth in the car. Or even women that tear open all the way to the anus because they delay going to the doctor."

Hospital protocol such as the use of electronic fetal monitoring prevents the women from employing their time-tested methods of ensuring vaginal births, which they find disempowering and aggravating. The women believe that by waiting at home, delaying arrival at the hospital, they give themselves a fighting chance for vaginal birth. Women described laboring at home, walking around though contractions until they dilate to six or seven centimeters and only then going to the hospital, believing that once labor had progressed so far, providers have no other option but to deliver vaginally. A middle-aged woman, mother of 12, all born vaginally, described the advice she somewhat-forcefully gave her Americanized daughter:

I gave her advice. But she is used to American culture. In my culture, we wait at least two days in labor...but she says c-section is easy. I told her to stay, stay, wait for the time god wills. She says no. She goes with the doctor [and gets a c-section]. I don't take her to the hospital now until she is well in labor. She had four children normally, other than the twins and the last child. Now, if she is in labor, I tell her to hold on until the child literally come out, and then she goes to the hospital to give a natural birth.

There is an apparent generational gap in this narrative, one revealing the strong influence and role of mothers in their daughters' health decision-making. After the daughter's last two pregnancies ended in c-sections, the mother felt certain in the importance of her advice.

Unfortunately, such well-meaning advice may end up backfiring, subjecting the daughter and her child to adverse outcomes. Following two previous c-sections and four other vaginal births, few providers would recommend that this woman attempt a VBAC, especially with a complete lack of medical supervision. Should any complications arise, no provisions will have been made for emergency care and with transport to the hospital, precious time is lost. Alarmingly, quite a few women with a history of c-sections described employing delay, hoping to avoid a subsequent c-

section. At times, these strategies fail, and the women end up being c-sectioned even after laboring at home for hours. Other times, women arrive at the hospital and discover that their fetus has died during their long labor. In the community's mind, however, those stories are greatly overshadowed by narratives of success—of women who delayed going to the hospital and gave birth vaginally as a result.

Curiously, I was unable to find much conclusive data documenting similar delay strategies as employed by Somali women interviewed in previous studies. Hernandez (2007) documented that a majority of her Somali interviewees admitted to remaining at home for as long as possibly, but other comprehensive studies make no mention of the strategy at all. I am highly doubtful that what is *the* dominant strategy of Somalis in Columbus is truly confined to such a localized area. Instead, I suspect that these are widespread behaviors, though with varying degrees of utilization, and perhaps more successful elicitation in previous studies would have revealed similar results. Moreover, the lack of awareness by providers, including those in Columbus, is highly revealing of the fraught relationship between providers and patients. As a result of the lack of trust and difficulties in communication, patients are not getting through to their providers regarding actions that invariably affect the course of woman's birth in a significant way.

Refusing the c-section

The wife was in pregnancy and I think some kind of emergency had to happen, like they had to give birth to the baby right away or something like that, and like the husband refused, the wife refused, they were like "we will trust in god". You know, they completely didn't trust [the provider] ... what ended up happening is the baby died in her stomach—Somali woman in the Columbus study

For biomedical providers, having dedicated themselves to the principle of "first, do no harm", watching a child die surrounded by the skills and technology readily available to save him or her is devastating. Having been trained to save lives whenever possible, respecting patients' cultural values in these cases proves immensely difficult for providers. They describe finding themselves emotionally distraught and angry after such interactions: "we said we thought she should have a c-section and they said, 'no, it's Allah's will it's Allah's will' and we watched the baby die and it was difficult" (Lazar 2008, 18). Providers describe trying numerous strategies to convince women to consent to an emergency c-section. At times, providers' manner of persuasion is harshly received by the Somali women, who feel that they are being given an ultimatum, coerced into having a c-section. "Her brother's wife, when she was in labor, they told her you can't leave, you have to sign this paper, and you don't have any choice but to do a csection, because if you leave, your child will die. And she did it. She went along with it... [Doctors] scare them." These persuasion techniques sometimes backfire. Riled by the lack of choice the women feel they are being given, some women react angrily by refusing the c-section altogether: "if I don't like what [doctor] says, he shouldn't force me to do it. But the doctors here, they force people to do what they want."

In Norway, Vangen et al (2000) document a strong resistance to c-section that resulted in instances of c-section refusal, even at the risk of the child and mother's life. Elsewhere, cases of Somali c-section refusal are also documented, mediated by fear of interventions and strong

desires for vaginal birth (Essen et al 2000, Hernandez 2007, Narruhn 2008). Not all refusals, however, are mediated by fear of interventions or mistrust of the necessity for the procedure. For many women, refusal of a c-section coincides with an educated acknowledgment of the risks involved with refusal. Here is a decision centered not only on present reality, but also on future potential; whereas providers understand the choice to be centralized on the life of the fetus, the women consider the lives of all the other potential children they might bear. The women are highly cognizant of the ways in which c-sections limit the number of children women safely bear. They reason that by refusing the c-section, even at the risk of losing a child, they make the choice not to risk the lives of any of the other potential children Allah has in store for them. As will be extensively explored in the chapter concerning personhood, these friction-filled encounters center upon a dissonance between Somali women and their providers concerning the concept of personhood, choice, and moral obligations. While providers acknowledge the effect of c-sections on women's fertility, they personally disagree with women's choices, and find them incredibly hard to stomach: "'cause if she really wants to have seven babies I don't want to do seven c-sections, because it gets more and more dangerous, but at the same time I'm not willing to sacrifice this child for six more, whereas she might be willing to do that" (Provider in Lazar 2008, 18).

Chapter 8: Personhood, morality and choice in the context of c-section refusal and courtordered c-sections

In the U.S Bill of Rights, the first amendment declares that religious and governmental institutions be kept separate and independent (U.S Constitution). These demarcation lines blur around the topic of fetal rights and personhood, one of the most contentious subjects in American culture (Heriot 1996). When a woman is pregnant with what may result in a child, there is no universally accepted designation for the "thing" developing within her uterus. While biomedicine is presented as detached from culture and morality, the decisions made by providers in regard to multiple healthcare decisions, including fetal rights, suggest differently. The present chapter analyzes several salient debates surrounding court-ordered c-sections with the goal of demystifying the decisions of Somali women who refuse c- sections and those of their providers, who frequently overrule the refusals of Somali women with the backing of the American legal system. The divergent decision-making processes of Somali women and health care providers regarding c-sections can be understood as a clash between two moral fields.

As a result of my long-term research on the decision-making strategies of Somali women during their pregnancies and after giving birth, I have concluded that for Somali women, pregnancy is acknowledged, but the life of the fetus remains undetermined until birth. Mother and fetus are one and inseparable. Rather, the ever-growing belly is a promise of a possible child. Biomedicine, on the other hand, relies on a wide range of technological devices to help monitor and track the wellbeing of fetuses. Visual imaging essentially allows the fetus to be regarded as an independent being, a second patient. "The power of visual technologies," wrote Sharp (2000), "lies in their uncanny ability to render the body transparent and thus easily penetrable" (300).

The pregnant woman's bodily integrity is then compromised as the fetus developing within a woman is embued with rights that may even come in direct opposition with those of the woman (Davis-Floyd 1994). Providers focus on the fetus, viewing it separately from the woman upon whose nourishment the fetus depends. This construction of the second patient creates a rift, a dichotomy between two separate beings—woman and baby (Casper 1994, Davis-Floyd 1994). It becomes unclear which patient's needs must take precedence over the other. In contrast to the ubiquity of visual technologies used in the U.S. medical system, in Somalia, women traditionally rely on external examination during pregnancy. With only 33 percent of births overseen by professionally trained providers, the vast majority of Somali women in the Columbus study had even never seen an ultrasound machine before their move to the U.S, let alone received an ultrasound (WHO 2006).

Within biomedicine, the woman's body undergoes commodification as well, to become a machine working to produce the ultimate product—the baby (Davis-Floyd 1994, Martin 1987, Sharp 2000). A woman's own birth experiences are now seen as tangential: she is a machine and her uterus is a part, highly susceptible to breakdown, in need of management in the form of obstetric interventions (Martin 1987). "The pregnant woman in fetal surgery [is] often referred to simply as 'mom' by practitioners... treated as obstacles, recalcitrant bodies that must be surgically penetrated to reach the primary patient" (Casper 1994,312). With focus centered on the fetus and approaches centering on the lack of reliability of women's bodies, women interviewed by Martin (1987) described feeling irrelevant and disempowered, feeling that their desires were viewed as obstacles, that they were selfish for caring about their personal experience as well.

When providers and patients disagree on notions of personhood and fetal rights, and providers have the power to physically enforce their morality on women's bodies, "the creation of an adversarial relationship between a pregnant woman and her health care providers' drives women out of the health care system" (Krauss 1991, 536). In the case of c-section refusal and court-ordered c-sections, the rights of women are pitted against those of their fetuses, creating a "fundamental dichotomy between the rights of the woman as a person and the rights of the fetus" (Heriot 1996, 180). Court-ordered c-sections are rare, but highly traumatizing and disturbing for both parties. In cases when women refuse c-sections, despite providers' perceptions that a fetus' life is in danger, providers may turn to the court system to uphold their decision. Court-ordered c-sections may be requested preemptively or during a woman's labor, when it becomes clear that she intends to refuse an emergency c-section (Levine 1994). Since the request for most courtordered c-sections takes place during a critical point in labor, decisions must be prompt. As such, judges may not have sufficient time to examine and analyze specific cases at hand, and some court-order requests are even done over the phone (Levine 1994). When women have refused csections for religious reasons, courts have typically overlooked the women's religious motivations for the refusal. Miller (2005) quoted one judge in a c-section court-order as concluding that, "the intrusion involved into the life of [the parents]... is outweighed by the duty of the State to protect a living, unborn human being from meeting his or her death before being given the opportunity to live" (389).

Though there has been no published documentation of Somali cases, court-ordered c-sections against Somali women have been reported to take place in Rochester, Minnesota³¹. The demographics of the women in the Harvard Law Review by Krauss (1991) reveal disturbing similarities of vulnerability shared by the Somali women in the Columbus study. According to

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³¹ This information was relayed to me in personal communication with Crista Johnson, November 22, 2009.

this Review, these women largely hailed from disadvantaged socioeconomic groups, a quarter of them did not speak English and 80 percent were of an ethnic minority (Krauss 1991). Krauss postulated that these demographic trends stemmed from the basic differences in morality between vulnerable women and the providers who care for them, bringing to light the power dynamics that allow certain moralities to gain precedence over others.

Discussing the development of distinctive moral fields, Arthur Kleinman (1999) wrote that "a person is located in economic, cultural, kinship, friendship, and work activities that powerfully define his or her moral horizon" (72). This is true not only for the establishment of the Somali women's judgments and moral ethics, but also for providers practicing in American hospitals. For Somali women in the Columbus study, belief in Allah and his predetermined will shapes many of the women's decisions to refuse c-sections. The religious beliefs underlying these choices is often misconstrued or misinterpreted by providers, whose statements regarding patients' choices reveal a deeply disturbing lack of respect. Krauss (1991) quoted one such provider as discussing a woman's refusal of a c-section as stemming from "the mother's ignorance and prejudice, which prevented her from arriving at an intelligent decision" (532). While some women refuse emergency c-sections out of a lack of understanding of its medical necessity, many simply do not agree with providers that c-sections are the best response to cases of fetal distress. Cognizant of the possibility that their unborn child may not live as a result of their refusal, Somali women's belief in the divine will of Allah is critical to their decisionmaking processes, even in face of the persuasion and fear mongering of medical practitioners. Allowing providers to intervene artificially with a c-section constitutes a breach in one's faith in Allah as the ultimate decision maker. Women experience loss with the death of a fetus, but faith in Allah's ultimate plan for them may help them find peace. It is when providers perform csections that Somali women feel are unnecessary, usurping Allah's power with the use of technology, that women feel profoundly disempowered by the outcome of their pregnancy.

Based on my experience working on the Columbus Study, I have become aware that for Somali women, life begins at birth. Even at full term, Somali women may not consider their fetus any more 'viable' than any other children they might bear in the future. Considering this context, the decision to undergo a c-section to save one potential child at the expense of multiple future children is hardly straightforward. The ways in which providers react to Somali c-section refusal reveal, at times, their opinion that Somali women who refuse c-sections do not value life and do not care about their children (Lazar 2008). These allegations risk being ethnocentric, insensitive, and untrue. It is a truism that motherhood is one of the most celebrated and desired roles in Somali women's lives. As for women in many societies, having children is one of the central aspirations of Somali women. Describing the importance of becoming a mother in Somali culture, Hernandez (2007) wrote that, "children cement a woman's link to her clan and provide security and sustenance...to not have children was seen as living an impoverished life" (195). Refusal of a c-section, then, is neither an indication of lack of motherly love nor carelessness about human life. Rather, it reflects a disagreement between providers and patients about what constitutes life and facilitates future wellbeing.

Somali women's concept of personhood, mediated by their faith in Allah, can be partially understood as an adaptive response to common experiences with infant morality in Somalia, where rates of infant and early-childhood mortality are especially high (Unicef 2010c). Many of the older women in the study described the loss of children before the civil war, likely a result of illness and perhaps malnutrition as well. Submitting to the will of Allah in determining the outcome of a pregnancy or the survival of a child is one strategy of coping with the loss of

children, a way to create order and control amid poverty and uncertainty. In her seminal ethnography *Death Without Weeping* (1992), medical anthropologist Nancy Scheper-Hughes similarly describes the ambivalence of Brazilian women to infant mortality. Sensitized to the reality that poverty gives some children little chance at survival, infant mortality was perceived as normal and uneventful. The death of a child was not marked by any immediate display of mourning and grief.

While Scheper-Hughes' thesis received fierce criticism³², it offers useful reflections on the socio-economic and cultural dimensions generating ambivalence toward infant mortality. Scheper-Hughes postulated that poverty had transformed motherly love, creating situations in which women deemed certain children as lacking the physical and mental fitness to succeed in their difficult environment, and thus resisting emotional attached to them. Motherly affection, Scheper-Hughes postulated, is a privilege of the rich. Rather than indifference, these responses to child death became a way to cope with the powerlessness women experienced as a result of the pervasive poverty and structural violence in their lives.

Somali responses to the death of fetuses following the refusal of a c-section have also received widespread accusations and judgments. Whereas the Brazilian mothers made sense of infant death by classifying certain children as having a weak will to live, Somali women make sense of the loss through their trust in Allah and his ultimate plan for them. Their reactions to the death of an infant—perhaps seen by outsiders as indifference—might be better understood as a coping mechanisms mediated by past experiences as well as religious and cultural frameworks.

For Somali women, the death of a child is a troubling, painful experience, but we should not assume that it is experienced in the same way as it is for women raised in America who are

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³² As Professor Mark Padilla discussed in lecture on November 1, 2009, some critics went as far as accusing Scheper-Hughes of romanticizing child abuse, referring to the Brazilian mothers decisions to let children die by slowly staving off the affection given to children they perceived as lacking a will to live (Padilla 2009).

accustomed to receiving care in biomedical facilities. Many of the Somali women in the Columbus study lost children in Somalia prior to immigrating to the United States. As a result of these past experiences with infant mortality, many women in the study seemed to accept its possibility in their births in the U.S as well, conceiving of these deaths as an unfortunate but often unavoidable aspect of motherhood. The rate of infant mortality in the U.S is abysmally higher than that of almost all other Western nations, but it is still nearly 20 times lower than rates in Somalia (CIA 2009); most American women and their providers trust that newborns will survive birth, even in the presence of complications.

The American conception of personhood for the fetus is also radically different than the Somali version. The biomedical concept of personhood is based in a Judeo-Christian theology, in which life is understood to begin at the moment of conception. Much of the legislation pertaining to issues of personhood in biomedicine in the U.S. Constitution can be traced directly to Christian roots. House Bill 1445 on informed consent before abortion defines gestational age by implying that "a fetus should be defined as an unborn child from the moment of conception onward" (Heriot 1996, 178). On a state to state basis, definitions of life become even more overtly biased. Missouri state law offers a singular view of personhood: life begins at conception, at which time fetuses are considered fully-fledged persons (Heriot 1996). It is important to observe that the so-called universal moralities on which this kind of legislation is passed are Judeo-Christian moralities. The legal system reflects an affinity to Judeo-Christian morality and "does not acknowledge the socially constructed nature of medical/scientific knowledge" (Heriot 1996, 185). Just as the influence of Islam and Somali culture must be acknowledged as affecting the Somali women's perceptions and decisions, so must that of biomedical providers.

Here, it is important to add that Somalis are not the only community that refuses medical treatment, even at the cost of a life, based on religious convictions. While many people who refuse medical treatment for religious reasons often belong to marginalized communities, it is instructive to compare the methods by which the biomedical community reacts to these various refusals of medical treatment in light of the political, social and economic power that each group yields.

Jehovah's Witnesses reject blood transfusions, and members have been known to die after refusing a lifesaving blood transfusion (AP 1981). However, despite some stigmatization of Jehovah patients, hospitals and providers all over the country began providing such patients with alternative treatment options such as the use of non-blood replacement fluids during operations (AP 1981). Likewise, Followers of Christ Church in Gladstone, Oregon—a group that believes in prayer in lieu of medical treatment—received nationwide attention in 2008 when a couple refused their son's medical treatment and were subsequently charged with criminally negligent homicide (FOX 12 2008). In response to the death of numerous Church children, Oregon state law now overrules the legal powers of parents in certain cases of faith-healing parents to provide children with medical care despite their parents' refusal (FOX 12 2008). Court-ordered csections are not exceptionally different than court-ordered medical treatment for children. In both cases, it is the legal system that determines which form of knowledge is accorded authority in cases of disagreement concerning medical treatment. The court system almost exclusively sides with biomedicine and its ideologies, and alternative forms of knowledge are discredited and stigmatized. However, there are striking differences between cases of court-ordered medical treatment and c-sections, one that lies in the entanglement of the fetal rights debate. When the court system orders a c-section to save the life of a fetus, it does do by overruling women's basic

rights to control over their body—that is, medical rights to refuse their own treatment. C-sections do not just "save" fetuses, they also subject women to a host of medical risks for complications, death included (ACOG 2006).

Despite being couched in scientific terminology, the decisions, protocols and outcomes of biomedical health experiences are defined by local moralities, constructed by culture, religion, politics, and economics. Like every other cultural system, biomedicine is based on socially constructed moralities appropriate for a particular population and environment (Martin 1987). Biomedicine is an institution with tremendous power and agency. Its actions toward fetal rights attach specific meaning to fetuses' lives and deaths in ways that uphold ties with particular religious and cultural moralities and not "universal truths." "Medical practice and expertise 'naturally' presents itself as designed for the best interests of mother and baby. Yet this is not necessarily the only view... Obstetrics has a long history of errors" (Krauss 1991, 325). Kleinman (1999) writes that clinical bioethics privilege "ethical" abstract universals over localized "moral" concerns. Krauss (1991) eloquently wrote that, "because rights are socially constructed, we must consider how and by whom rights are defined and exercised in light of current social and economic conditions" (544).

When providers overrule patients' choices, they effectively destroy any illusion of equality between them and their patients. Here, they are seen to take full advantage of the power granted to them. The woman's own desires, rights, and choices cease to be acknowledged. "Fetal-endangerment persecutions thus destroy the honesty and collaboration essential to the doctor-patient relationship by transforming physicians into agents of the state" (Heriot 1996, 535). As a result of the great power vested by the U.S government in biomedical institutions, providers are able to seek legal action against "dissenting" women, subjecting them to an

unwanted procedure and thereby brutally negating their rights. Court-ordered c-sections are an effective denial of any alternative forms of meaning and morality.

Andrews and Nelkin (1998) wrote that,

A person's control over what is done to his or her body, or its parts, is important to the individual's psychological development and well-being. It is also a means to establish identity and convey values to others... Social conceptions of the body establish community identification, encourage socially responsible behaviors, and set acceptable priorities for group activities (54).

When women are removed by physical or rhetorical force from decision-making power over their own birthing experiences, it is not only the one birth, the one woman who is affected. The reverberations of the disempowered birth echo throughout the Somali community, one more negative experience added to the weighty pile.

Chapter 9: Conclusions

Providers seem disturbingly unaware of the strategies Somali women are regularly undertaking to avoid c-sections, sometimes at the risk of their own lives and that of their fetuses. There are ways in which the healthcare system can be blamed for the gap in understandings; demanding schedules restrict patient-provider interactions to as little as ten minutes, lack of appropriate translation services can impede, and at times even derail communication (Deckard, Meterko and Field 1994). At the core, however, is distrust. The Somali study reveals the many ways in which providers and patients' perceptions of care are exceptionally disparate. When a Somali woman's labor ends in a c-section, providers may be aware that the woman is unhappy, but they largely remain bewildered at the level of despair the women expresses as a result. In a medical culture that delivers a third of babies via c-section, these operations are seen as routine (Menacker and Hamilton 2010). It is painfully clear from the women's own narratives that for Somali women, c-sections are in fact not only radical but also devastating. There is a lack of established trustful dialogue between providers and patients, and neither "side" is getting through to the other about the experiences they share, in the same room, but worlds apart.

Both providers and Somali women have stopped seeing the other as partners in health but rather as adversaries in the courtroom. When women feel put on trial during medical examinations, perceiving that if they admit to their "crimes," they will be punished with a c-section, it is no wonder that they chose not to disclose their true actions and behaviors. For providers to truly provide appropriate care, they must be aware of these practices, these strategies, these fears. Bridging the gap between providers and patients necessitates more than pamphlets in Somali or female genital cutting workshops for providers. Patient education and advocacy are crucial, as are better translation services that include cultural brokers.

A recent c-section refusal case from Phoenix, Arizona illuminates the ways in which education is not enough. This woman is not a new immigrant confused about the foreign medical system and its laws; she is a Somali U.S-trained doctor, who refused her own c-section at the request of her mother. Having been trained in advanced biomedical techniques and practices, fully aware of the choice she was making and their implications, she refused, and the fetus eventually died. The role of Somali networks of support and the social pressures within them must be acknowledged and respected. The mistrust is at the community level, a saturation of bad experiences that overshadows positive ones. Just as the women's networks can mediate mistrust, so too can they facilitate trust. Changes must take place on the individual and community level.

There are tangible signs of improvement.

At the Mayo Clinic in Minnesota, a team of providers led by Pricilla Flynn launched a Somali education prenatal video, aimed to provide culturally appropriate information to women. Used in conjunction with prenatal visits, the video addresses the specific needs, perceptions, and fears of Somali women giving birth in the U.S. Providers are able to overcome communication barriers posed by illiteracy among Somali women through the use of a videos in Somali. The video covers nutrition, exercise, translation services, preparation for birth, and the role of fathers. Importantly, the video also addresses misconceptions and myths about c-sections and birth in U.S hospitals, providing information about medical routines, procedures, and risks. A majority of Somali women documented in a study of the video found it to be helpful, and providers stated that prenatal exams have become more effective (DeStephano, Flynn and Brost 2009).

In 2002, a Somali doula³³ program was established at a Minneapolis hospital serving a large Somali community. The doulas were recruited from the Minneapolis Somali community and trained by the hospital, where they work on-call. Doulas explain birthing procedures to women, provide emotional support during the birth, and advocate for women. Among Somali women who gave birth with the support of a doula, c-sections rates were nearly halved, and both women and providers described feeling more comfortable and trusting of each other (Dundek 2006).

Finally, clinics such as the Refugee Women's Health Clinic (RWHC) in Phoenix,

Arizona—that are tailored to the unique obstetric and gynecological needs of circumcised

women—provide a safe environment in which the needs, perspectives, and perceptions of

women are acknowledged and addressed. At RWHC, community outreach is a key factor in

facilitating positive experiences for women at the clinic. By creating prenatal informal meetings

for women in their own neighborhood, trusting relationships with the clinic are created even

before women seek medical care.

Prenatal centering is a similarly innovative method of distributing information, sharing experiences, and developing trust. Centering refers to practice of educating women about prenatal examinations in groups. Surrounded by peers at different stages of their pregnancy—but who share similar experiences, perceptions and fears—women are able to share knowledge and experiences while simultaneously engaging with providers in an in-depth and informal way. Moreover, the group structure allows providers to spend more time explaining procedures and expectations in a format that is conducive to more honest, compassionate dialogue (Rising 1998).

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³³ Doulas provide social support to laboring women and their partners, both in terms of physical comfort and emotional support. Different types of doula care exist, but in the case of the Somali doula program, doulas are paired with women upon their arrival to the hospital and do not maintain contact following the birth. Doulas typically stay with women through the entirety of their birth, providing guidance and facilitating communication between providers and women (Dundek 2006).

Though no published material exists surrounding centering services for Somali women, initial projects in Chicago are promising³⁴. While issues of distrust and miscommunication are not easily overcome, the intentionality with which multiple programs across the country structure their care allows for new, active collaborations to be formed between the Somali community and their providers.

In terms of the disagreement between providers and patients surrounding treatment and care, the issue is hardly that providers do not have their patients' best interest in mind; rather, providers believe they know best and often implement their beliefs by force. Providers are aware that trust must be re-established with the Somali community, but are unwilling to give up their right to make the final decision. As long as court-ordered c-sections remain a possibility, however remote, patients cannot fully trust their providers. Providers must acknowledge and dismantle the fears of Somali women directly, demystifying women's experiences with csections and outlining the ways in which they can work together to try to avoid them. These conversations must take place before fetal heart monitors begin beeping, during prenatal and well-women examinations. Hospital protocols must change to find ways for providers to spend more time explaining procedures and educating patients about self-care so that they make educated decisions. And then, providers must allow women to make them.

My conclusion then, is that when a woman refuses a c-section after fully informed about her choices and risks, she must be allowed to do so, as hard as it may be personally for providers. A woman must always remain the ultimate decider about her own body and its integrity. In the long-term, outlawing court-ordered c-sections and letting women know that their bodies cannot be violated against their will, will facilitate more trust and dialogue and less necessity for women take independent action in the first place. Then, work with providers can begin in earnest with

³⁴ This information was provided to me by Nicole Warren CNM in personal communication, May 18, 2009.

the goal of improving the health outcomes of women and babies. Landrine and Klonoff (2004) write about the ways in which community behavioral patterns change and are replaced over time, when they are no longer perceived as necessary: an "extinction of prior, culturally-normative behaviors because of the loss of the indigenous cultural context that had maintain them" (538). Change happens, even if gradually. It is probable that some fetuses will die when c-sections are refused. Eventually though, positive birth experience can begin taking the place of disempowered ones, and Somali birth outcomes will improve—as will the lives of children born to women more confident in their experiences and providers.

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