"WHAT YOU HIDE ALSO HIDES YOU"

MENTAL HEALTH SCREENING, RISK FACTORS, AND SERVICE USE AMONG A POPULATION OF SOMALI WOMEN IN THE U.S.

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Abstract

i. Background

Like other refugees, Somalis have increased mental health risk due to pre- and post-migratory trauma and stress. Additionally, researchers hypothesize that female genital mutilation/cutting (FGM/C), a nearly universal Somali practice, increases risk. Despite this, Somali women have comparatively low uptake of referrals to psychological services. Study aims were to assess the validity of a common mental health screener, explore potential risk factors for distress, and understand how community discourses encourage or constrain mental healthcare seeking behavior.

ii. Methods

Data collection took place in 2017-2018 in the state of Arizona. Somali women age 15+ were included in a quantitative community health needs assessment (CHNA) using respondent-driven and snowball sampling (N=879). Twenty-four focus group discussions with both men and women (N=168), sampled purposively, provided qualitative data. The Refugee Health Screener (RHS-13) was used to assess clinically significant distress. Validation utilized factor analysis and comparisons with related constructs. Multivariate logistic regression explored predictors of distress and qualitative transcripts were analyzed using critical discourse theory.

iii. Results

Factor analysis of the RHS-13 returned a 1-factor solution, similar to prior validations. Associations between positive screens and external constructs were significant in expected directions. Approximately sixteen percent met the cut-off criteria

for clinically significant distress (n=118). There was no clear association between FGM/C-status and distress in multivariable analyses. Among circumcised women, those reporting adverse health experiences at the time of circumcision were more likely distressed (OR=4.29;95%CI 1.68-10.97). Potentially traumatic experiences (OR=8.94;95%CI 3.81-20.98) and perceived discrimination (OR=2.90;95%CI 1.20-7.02) were also predictors. Qualitative analysis revealed nosological fusion of psychiatric illness terms and the importance of community social control to limit disclosure. US health services were described as giving off a "bad vibe", and represented external institutions of power. Three negotiating discourses emerged wherein participants created discursive solutions to maintain Somali identity while accepting US mental care.

iv. Conclusion

The RHS-13 appears valid for identifying clinically significant distress among Somali women. The experience of FGM/C continues to impact the mental health of some women, though not all experienced FGM/C as a traumatic event. Qualitative findings suggest psychological services are seen as an affront to Somali identity making.

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When I heard the learn'd astronomer,
When the proofs, the figures, were ranged in columns before me,
When I was shown the charts and diagrams, to add, divide, and measure them,
When I sitting heard the astronomer
Where he lectured with much applause in the lecture-room,
How soon unaccountable I became tired and sick,
Till rising and gliding out I wander'd off by myself,
In the mystical moist night-air, and from time to time,
Look'd up in perfect silence at the stars

-Walt Whitman

Acknowledgements

I would like to acknowledge the strength and resilience of the Somali community and especially those whom I collaborated with on this project. I thank them for their generosity and wisdom. Furthermore, I would like to acknowledge the entire Arizona research team, including the staff of the Refugee Women's Health Clinic and the Southwest Interdisciplinary Research Center. Their dedication to community-based methods and to serving the refugee community in Arizona is inspirational, and I feel honored to have been a part of their work. In particular I would like to acknowledge Dr. Crista Johnson-Agbakwu & Jeanne Nizigiyimana, who have mentored me spanning back nearly a decade, to when I first entered the clinic as a volunteer. We have seen hard times, and wild times, and wonderful times, and I am forever grateful to work beside you. Many thanks as well to my entire Hopkins-based mentorship team, including Drs. Pamela Surkan, Judy Bass, Maria Merritt, Joe Gallo and Nicole Warren. What an extraordinary group of scholars to have learned from; I am humbled. I would like to thank my friends, especially Jamie Carrillo & Brittany Jock who have on more than one occasion been my rocks. Finally, I thank my wild-haired, incomparable mother, who forever reminds me to never stop looking up in wonder at the stars.

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List of terms and abbreviations

Community-Based Participatory Research (CBPR)

Confidence Interval (CI)

Department of Health and Human Services (DHHS)

Eigenvalue (EV)

Female Genital Cutting (FGC)

Female Genital Mutilation (FGM)

Female Genital Mutilation/Cutting (FGM/C)

General Health Questionnaire 12 (GHQ-12)

Modified Bicultural Involvement Questionnaire (M-BIQ)

Odds Ratio (OR)

Patterns of Cultural Involvement (PCI)

Potentially Traumatic Experiences (PTE)

Post-migration Living Difficulties (PMLD)

Post-traumatic Stress Disorder (PTSD)

Receiver Operating Characteristic (ROC)

Refugee Health Screener 13 (RHS-13)

Refugee Women's Health Advisory Coalition (RWHCAC)

Refugee Women's Health Clinic (RWHC)

Respondent Driven Sampling (RDS)

Standard Deviation (SD)

World Health Organization (WHO)

Chapter 1. Introduction

1.1 Study objectives

This study sought to identify effective pathways to mental health care for a vulnerable population of refugee and immigrant women in the United States, historically unengaged in mental health services. The research took a mixed-methods approach (Creswell, Plano, Gutmann, & Hanson, 2003; R. Burke Johnson & Anthony J. Onwuegbuzie, 2004) and was nested within a multi-armed 3-year study to improve health services for Somali women who have undergone female genital cutting/mutilation (FGC/M) (WH-AST-16-002).

Somali women and girls report the highest prevalence (98%) of FGC/M in the world (UNICEF, 2016). The World Health Organization's (WHO) 2016 guidelines on the treatment of FGC/M have strongly encouraged additional research on the psychological wellbeing of FGM/C-affected populations, with particular attention to the psychological consequences of FGM/C and appropriate intervention strategies for treatment (World Health Organization, 2016). Beyond the population's high rates of FGM/C, Somali women in the US are intersectionally disadvantaged on several other fronts, and can be considered a vulnerable population (Greta R Bauer, 2014). Each of these vulnerabilities, in isolation, have the potential to increase risk for poor mental health in certain contexts, and include gender, race, religion, immigration and refugee status, poverty, history of trauma, acculturation and discrimination, sometimes experienced in the healthcare setting (Aragona, Pucci, Mazzetti, Maisano, & Geraci, 2013; Behrendt & Moritz, 2005a; Bentley, Thoburn, Stewart, & Boynton, 2012; Betancourt, Frounfelker, Mishra, Hussein, & Falzarano, 2015a; Ellis, MacDonald,

Lincoln, & Cabral, 2008a; Ellis et al., 2010; Lincoln, Lazarevic, White, & Ellis, 2016; Pumariega, Rothe, & Pumariega, 2005; Wedel, 2011).

Complicating US public mental health efforts to provide care to FGM/C-affected Somali women are low rates of mental health service use among Somali refugees. While a mental health screener for refugee populations(Hollifield et al., 2013; Hollifield et al., 2016), available in the Somali language(Pathways to Wellness, 2011), is widely used, it has not been validated in the Somali population and Somali women rarely follow up after screening on the mental health referrals they receive(Johnson-Agbakwu, Crista E., Allen, Nizigiyimana, Ramirez, & Hollifield, 2014). The culmination of these effects is a relatively high need for mental health services among Somali women in the US, combined with low service use. In order to better understand the psychological wellbeing and service use of this group the following aims were explored:

Aim 1 evaluated the validity of the Refugee Health Screen 13 (RHS-13) through factor analysis and external construct validity. The RHS-13 has not been previously validated among Somali women, despite wide use. Increased confidence in its validity will support current referral systems as well as endorse public health and epidemiological evidence generated utilizing the screen.

Aim 2 explored the relationship between FGM/C and clinically significant distress. Current percent positive screens provide evidence of unmet need, while the exploration of risk factors uncovers at risk segments of the population, and elucidates the possible association between FGM/C and mental health.

Aim 3 identified how discourses around Somali mental health and service use encouraged or constrained the mental health seeking behavior of Somali women.

Aim 3 follows a sequential, explanatory mixed methodology framework, in that its data serve to both explain and expand on the quantitative findings of Aims 1 & 2. Qualitative transcripts from 24 focus groups of Somali men and women were analyzed using critical discourse analysis. Community discourse is likely to shape how women view their mental health needs, if they seek care, and from whom.

1.2 Epistemology & Conceptual framework

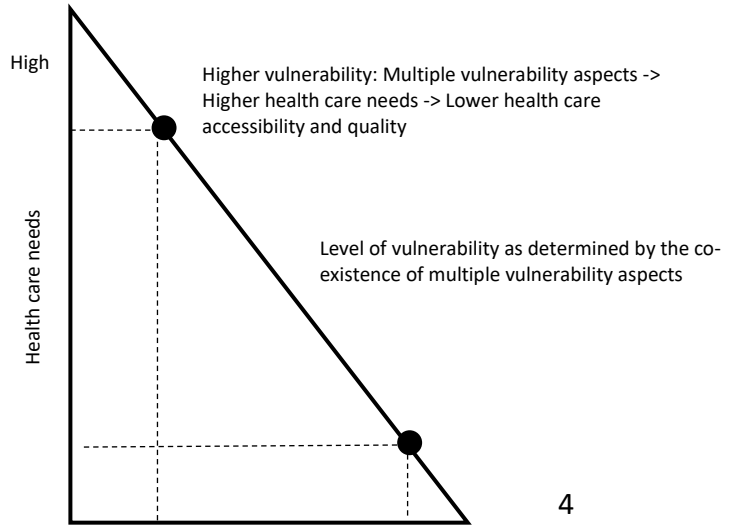
Epistemologically, Aims 1 & 2 of this thesis proceed from the positivist position, which assumes that Truth exists and can be accessed, while Aim 3 proceeds from the social constructionist perspective, assuming that individual truths are created within social spaces; that people 'exist' in language(Gergen, 1985). In explanation of this dualism, the following thesis work is grounded in the pragmatic research paradigm. The pragmatic standpoint assumes that 1) both objective and subjective truths exist depending on conditions, 2) the primary goal of research should not be to uncover any particular notion of reality (objective or subjective), but to be useful, and 3) mixed methods approaches to research design, where quantitative and qualitative methods are used to practically expand our understanding of the research questions, are useful (Yvonne Feilzer, 2010).

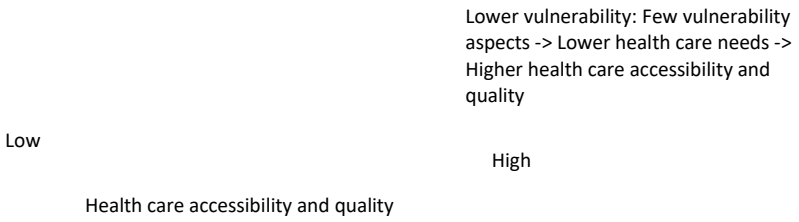
Laid atop the pragmatic stance, this proposed study is also theoretically grounded in critical theory, with critical theory itself being explicitly pragmatic. Critical theory expects that researchers will consider and account for their political, epistemological and ethical groundings during research design. Broadly writ, theory is "critical" when its intent is the liberation or emancipation of marginalized groups. Three specific criteria of a critical approach are that the endeavor be explanatory, practical, and normative, meaning that it

must explain what is wrong, and identify the actors and achievable practical goals to inform change (Bohman, 2016). The orientation of this research takes into account not only the orthodox political economy as described by Marxist philosophers, but other aspects of the social economy which contribute to or deter from health. In the tradition of Critical Medical Anthropology this research defines health as "access to and control over the basic material and non-material resources that sustain and promote life (Baer, Singer, & Johnsen, 1986)."

As exposure to multiple vulnerabilities increases, so too may health care needs, not only in additive, but possibly multiplicative ways (Figure 1)(Grabovschi, Loignon, & Fortin, 2013; Greta R Bauer, 2014). When combined with lower health care accessibility and quality, "vulnerability" may be an etiology for poor mental health and also a contributor to lack of care. Commonly cited aspects of vulnerability which have been associated with poor mental health include gender, race, religion, immigration and refugee status, poverty, history of trauma, acculturative stress and discrimination (Aragona et al., 2013; Behrendt & Moritz, 2005a; Bentley et al., 2012; Betancourt, Frounfelker, Mishra, Hussein, & Falzarano, 2015b; Ellis et al., 2008a; Ellis et al., 2010; Lincoln et al., 2016; Pumariega et al., 2005). Somali women in the US may have many, if not all, of these vulnerabilities. These vulnerabilities may lead to greater health care needs and lower health care access.

Figure 1. Health Disparities Framework (Grabovschi et al., 2013)





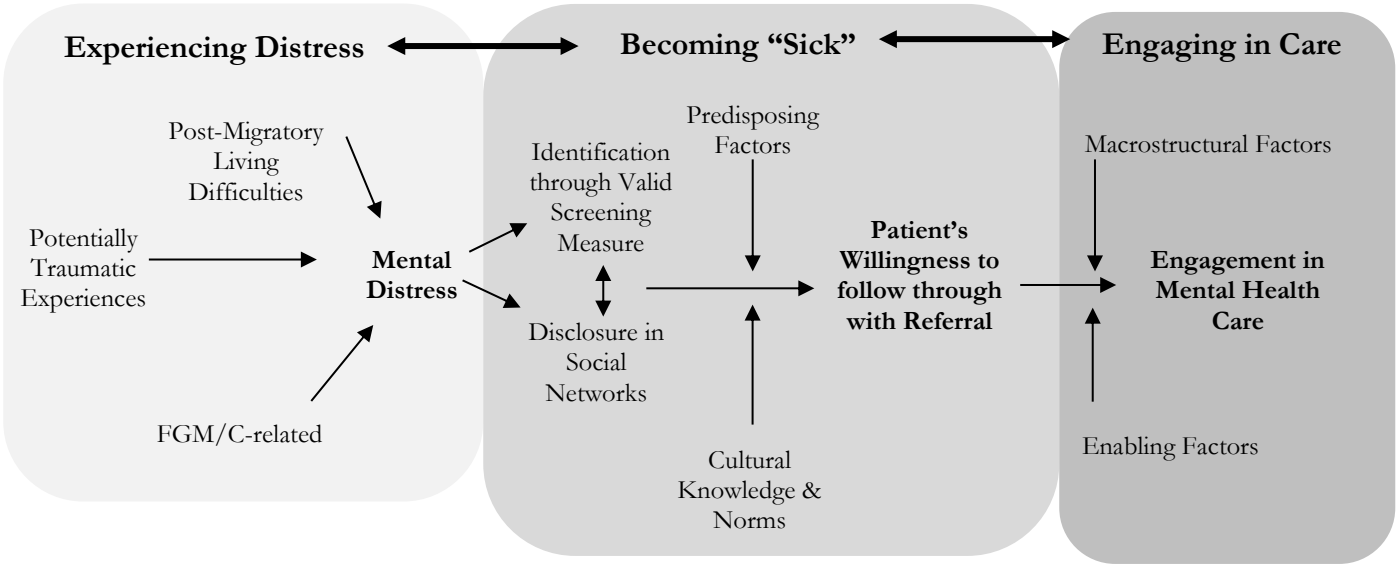
Vulnerable populations in general are more susceptible to physical and psychological harm (ten Have, 2016) and more likely to have multiple health concerns (Grabovschi et al., 2013). Further, vulnerabilities are often created and reinforced by the dominant societies in which vulnerable peoples live, meaning that vulnerability is an inherently ethical societal concern (Aday, 2002). When considering the vulnerability of Somali women and their mental health in the US context, it is necessary to contextualize this vulnerability. This study proposes that Somali identity in the United States is to be understood both as a cultural variate and a social construction occurring within the American hegemony. This stance aligns with critical race theory, which instructs that race/ethnicity/culture/otherness is not a natural category, but an ongoing event of difference-making (Moodley, Mujtaba, & Kleiman, 2017). Indeed, Somalis describe experiencing "blackness" for the first time in the American context, "for not only must the black man be black; he must be black in relation to the white man"(Fanon, 2008).

The discipline of public health can benefit from critical race theory by enhancing race consciousness and contextualizing marginalization during the research design and analysis process, as well as better understanding how research findings might be useful in practice (Ford & Airhihenbuwa, 2010b). For instance, critical race theory has been used previously to understand how experiences of discrimination in HIV clinics may prevent

African American individuals from being tested for the virus, a research objective pertinent to this thesis study (Ford & Airhihenbuwa, 2010a).

Difference, discrimination and vulnerability exist within socially created and enacted power structures. A vulnerability framework, drawing on intersectional and critical race theory, allows for the analysis of this power and, in turn, how mental health and mental health care seeking is experienced within this enactment. This analysis nods at the fact that overcoming disparities in mental health may require interventions at the individual or clinical level, as well as aspects of social inclusion and institutional support (ten Have, 2016). Its goal is neither to categorize nor Orientalize the vulnerabilities experienced by this group (Said, 1979).

Figure 2. Conceptual Model for Pathway from Distress to Care for Somali Women in the US



The conceptual model (Figure 2) posits the pathway through which Somali women might navigate to mental health services in the United States. This conceptual framework is a modification of the Behavioral Model of Health Services Use (Andersen, 1995) and proposes that there are three domains individual illness and treatment seeking affecting service use: (1) the individual factors leading to the experience of distress, (2) assuming or being labeled with a "sick" identity through interaction with institutions or other social structures, and (3) engagement in and experiences with care.

In a linear, directional sense, distress is first created and then experienced by the individual. Current clinically significant distress might be due to traumatic experiences, post-migratory living difficulties, or hypothesized factors related to FGM/C. In this domain, the distress is still internal to the individual, but as it moves to the second domain that experience of distress is filtered and reformatted through social and institutional lenses as the individual is marked as "sick". This social marking may occur either through institutional screening through a measure such as the RHS-13, or it may result from disclosure of mental

health concerns within the community. Whether or not an individual will then accept the identity of the sick role (agree with the results of the screen/be willing to assume the role of an individual with poor mental health in the family or community) with depend both on predisposing factors and cultural knowledge and norms. Assuming that the screen itself is valid, an individual's engagement in mental health services is largely contingent upon their willingness and ability to follow through with that referral.

After receiving a positive screen and subsequent referral, predisposing and cultural factors might influence their willingness to follow through with referral. **Predisposing factors** might include prior service use, acculturation, age, trust in healthcare, or prior experiences of discrimination by healthcare workers. **Cultural Knowledge & Norms** which may impact an individual's willingness might include concerns around stigmatization, or explanatory models for the causation and treatment of mental health not aligned with western medicine.

Assuming an individual is willing to follow through with referral, that individual must then be able to do so. **Enabling factors** to service usage might include having health insurance, access to transportation, or services available in your language. Hospitable **Structural Factors** must also be present, such as meaning that the individual must feel the ability to access mental health services without fear of discrimination.

These factors of influence may exert themselves from many levels of the social ecology, meaning at the individual, household, community, and broader social and structural levels. While presented linearly, this model is not meant to represent a directional graph, but assumes reciprocal events in the experience of distress, being assigned the role of "sick" through screening or disclosure, and engagement in the social act of health service use. In

other words, the conceptualization of this study as a whole understands the illness experience to be both individual and social.

1.3 Organization of the dissertation

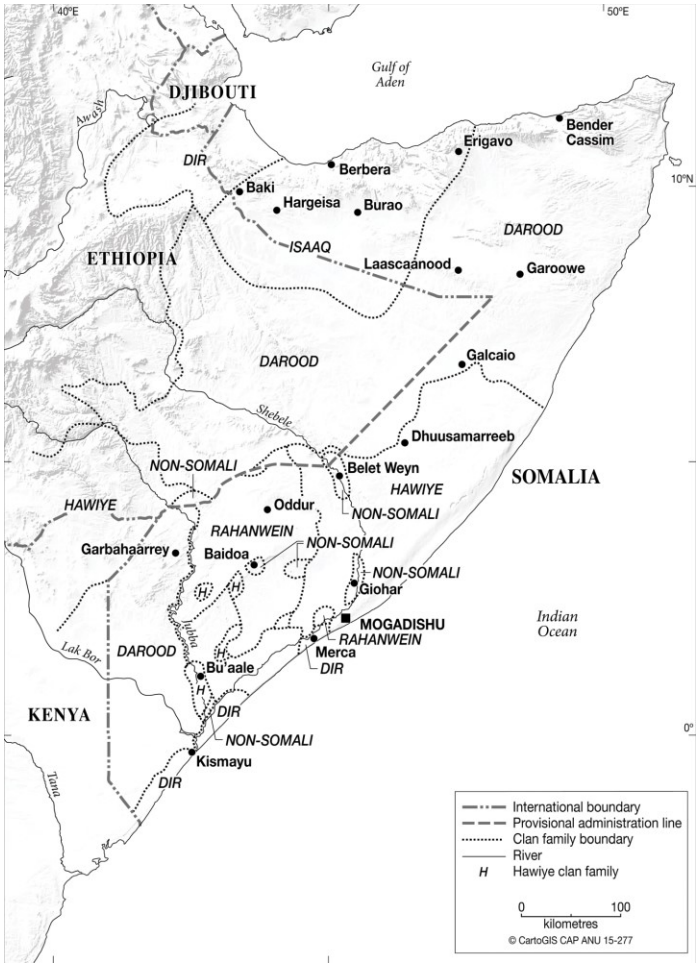
This dissertation is organized into 8 primary and 3 secondary chapters. Chapter 1 provides a brief overview of the aims of the dissertation and orients the reader to the epistemological and conceptual stance from which the analysis proceeded. Chapter 2 offers a landscape of the literature pertinent to the research and orients the study setting. Chapter 3 gives an overview of community-based participatory methods of the research overall and the mixed method approach which integrates the three aims. The methods of each individual aim are provided in the subsequent Chapters 4-6, which outline the background, methods, results, discussions and conclusions of each aim including: Chapter 4 Properties of the Refugee Mental Health Screener (RHS-13) among Somali Women in the US State of Arizona, Chapter 5 Female Genital Mutilation/Cutting and Psychological Distress among Somali Women in the United States, and Chapter 6 "Whatever You Hide, Also Hides You": A Discourse Analysis on Mental Health and Service Use in an American Community of Somalis. Chapter 7 provides a narrative integration of the three aims and final conclusions as well as recommendations for future research and public mental health intervention efforts. Chapter 8 provides a reflection on US and international public health and refugee policy as it pertains to Somali migrants and FGM/C. The three final chapters include Chapter 9, an appendix of the instruments used, Chapter 10, references, and Chapter 11, the author's curriculum vitae at the time of the dissertation.

Chapter 2. Literature review and study setting

2.1 The Situation in Somali & Immigration to the U.S.

Somalia, located in Eastern Africa on the Horn of Africa, collapsed into civil war in 1988, after decolonization by the British and Italian governments and two decades of socialism (Figure 3). From this time, Somalia fractured into smaller regional governments, some more stable than others. A nation-wide transitional government was formed in 2000 and ended in September 2017 when clan

Figure 3. Map of Somalia Showing Clan Family Areas (Bou, Breen, Horner, Pratten, & de Vogel, 2018)



elders elected a permanent parliament, which in turn elected Somalia's first president (CIA, 2017). The decades of internal conflict and famine resulted in millions of internally displaced persons as well as millions of Somali refugees worldwide. While efforts to repatriate Somali migrants are underway, with over 33,000 individuals returned to Somalia in 2016, the country remains largely unstable, with the terrorist organization Al Shabaab continuing to control large regions in the South (UNHCR, 2017). Somalia's current instability is perhaps best evidenced by the October 2017 terror attacks in Mogadishu, the capital city, where a suicide bomber detonated a large device, killing hundreds (Burke, 2017).

The role of clan elders, traditional institutions and clan membership has been vital to the identity of the Somali people and the reconstruction of Somali governance throughout the civil war (Renders, 2007). Five major clans and many smaller ones, based on blood relation or shared territory, represent the basic social unit of Somali society. The needs of clan members are addressed through the activities of a clan elder, who works in collaboration with the clan's Islamic leaders to provide governance, identity and political voice (Abdullahi, 2017). Clan membership and political disagreements between the clans remains a part of Somali social existence even after immigration.

While the historical, political and cultural context of the Somali people is unique, they are one of many groups that immigrate to the US. The US Census Bureau in the 2008-2012 American Community Survey estimated that nearly 40 million individuals born in foreign countries now live in the United States (Grieco et al., 2012). Of these, 1.6 million are from Africa, with migration from this area increasing since 1990 due to conflict and the draw of educational and employment opportunities (Gambino & Trevelyan, 2015). Those arriving as refugees or asylum seekers from conflict-affected areas in Africa represent roughly one quarter of this population. There are approximately 76,000 foreign-born Somali refugees

living in the US making up 4.8% of the African foreign-born population (Gambino & Trevelyan, 2015). When including Somali migrants of non-refugee status that number is doubled to roughly 150,000 Somali's currently residing in the United States (Connor & Krogstad, 2016).

While the majority of the Somali diaspora live in refugee camps or as migrants in the neighboring countries of Kenya and Ethiopia, the United States houses roughly 7% of the world's Somali migrant population (Connor & Krogstad, 2016). The number of Somali migrants and refugees to the United States has been steadily increasing, though in the second quarter of 2017 there was a marked decrease in refugee arrivals (Department of Homeland Security, 2017). The long term effect on immigration trends engendered by the Trump administration's travel ban in early 2017 as well as the enhanced ban announced in September, is yet unknown (Trump, 2017a; Trump, 2017b). However, given that these executive orders proclaim Somali migrants specifically to be potential terrorist threats to the United States it is plausible to hypothesize that Somalis both migrating to, or already living in the US are exposed to hostile, discriminatory environments.

2.2 Immigration & Mental Health

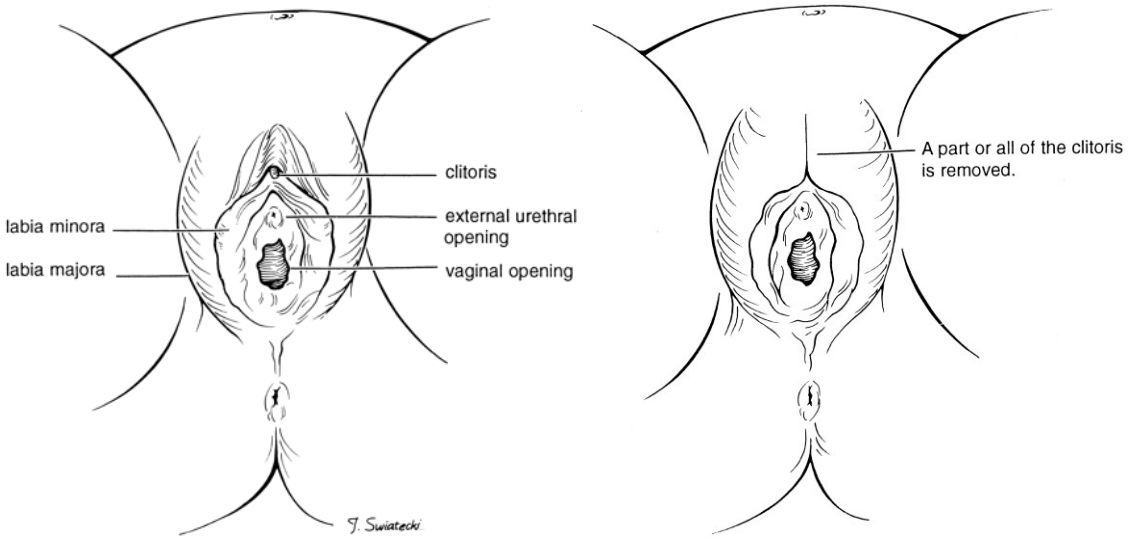
Many people who immigrate to the US are faced with challenges that put them at risk for a range of mental disorders. Such challenges include loss of social networks and support, language barriers, poverty, discrimination and acculturative stress, often referred to in summary as post-migration living difficulties (PMLD). Acculturative stress is best understood as the impact on an individual's mental health resulting from an attempt to adapt to a new social and cultural environment (Pumariega et al., 2005). Mental health services may

be especially needed for immigrants arriving from conflict-affected areas, since trauma from potentially traumatic events (PTE) may amplify the effect of other stressors (Aragona et al., 2013). PMLD has been shown to be a moderator between PTE and depressive symptoms among Somali refugees (Bentley et al., 2012), and perceived discrimination may trigger depressive symptoms among adolescent Somalis in the US (Ellis et al., 2008a). Immigration-related stress is not limited to first generation arrivals (Pumariega et al., 2005). Second generation immigrants who were born in the US, but raised by immigrant parents are often faced with similar post-migratory stressors such as poverty or discrimination. Similarly, their mental health may also suffer.

2.3 Female Genital Mutilation/Cutting

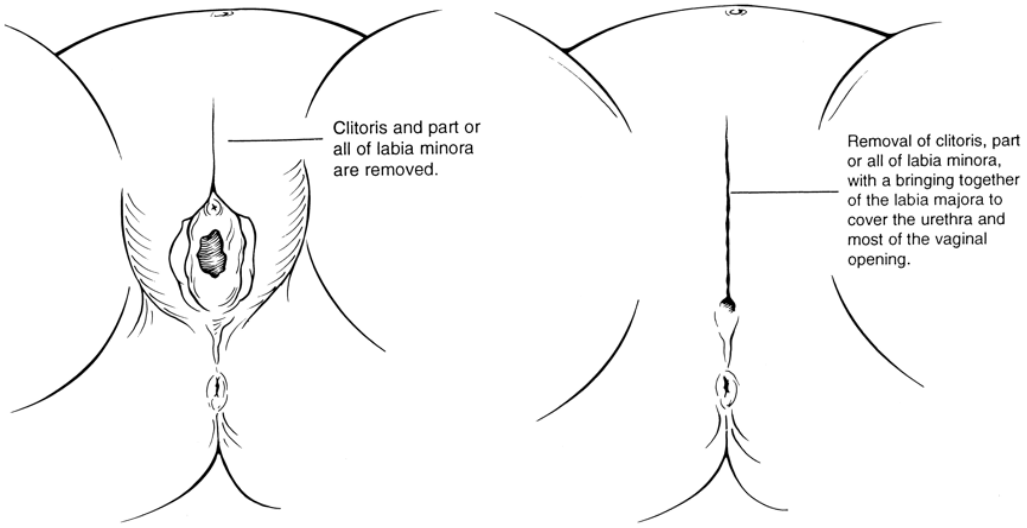
The WHO as an international institution representing biomedical knowledge and international human rights frameworks, uses the term Female Genital Mutilation (FGM) to describe any modification to the female genitalia including cutting, stitching, and burning, among other modifications, for non-medical purposes (World Health Organization, 2016). The WHO organized FGM/C into 4 major classifications Type I-III (Figure 4) and a Type IV miscellaneous category for all other procedures not covered under Types I-III (World Health Organization, 2016).

Figure 4. Types of Female Genital Mutilation/Cutting **(Committee on Bioethics, 1998)**



TYPE II

TYPE III



Terminological differences between cultural and academic spaces (Female circumcision, Female Genital Cutting (FGC), Female Genital Mutilation (FGM), Female Genital Mutilation/Cutting (FGM/C)) do not describe different procedures, but arguably represent differences in value judgements placed on this cultural practice. The Somali people most commonly refer to the procedure as "female circumcision." While there are several

forms, ranging from the use of a needle to ritually draw a single drop of blood from the clitoral hood (referred to as Sunna form, WHO definition: Type I), Somalis most regularly practice the most severe type, referred to in the community as the Pharaonic form (WHO definition: Type III), which includes both the removal of tissue as well as stitching of the vaginal opening, leaving a small orifice approximately the size of the head of a Q-tip through which urine and menstrual blood may flow (World Health Organization, 2016)

Human rights groups and the World Health Organization consider the cultural practice to be a form of gender based violence, especially given that it is often performed on girls under the age of consent; hence the term Female Genital Mutilation (FGM). Individuals with more pluralistic views of ethical conduct, such as anthropologists, propose that these practices (while they certainly should neither be excused nor permitted to continue) are better understood within the cultural context. They warn against the pitfalls of assuming an aggressive rights-based approach to intervention planning in this population, instead calling for "careful deliberation" (Shell-Duncan, 2008). For these reasons, many academics use the term Female Genital Cutting (FGC), which is believed to be less value-laden. This proposal will use the term FGM/C, nodding to both the biomedical and culturally-grounded production of knowledge around the procedure.

Somali women therefore experience, above and beyond the PTE and PMLD shared with their male compatriots, unique health and social risks associated with their experience of FGM/C. A study in Senegal found that women reported flashbacks to the event of circumcision, and while it is unclear whether or not FGM/C represents an independent risk for poor mental health, that study reported higher rates of PTSD and other psychiatric syndromes among women with FGM/C versus without (Chibber, El-saleh, & El harmi, 2011).

2.4 Vulnerability and Mental Health

Somali women in the US are an intersectionally disadvantaged group and a vulnerable population (Greta R Bauer, 2014). Intersectional theory proposes that people who are marginalized on several fronts can experience these marginalizations in amplified ways that are more than simply the sum of their parts (Kimberle Crenshaw, 1991). In the case of Somali women, disadvantage and discrimination may be derived as a result of intersectional experiences of racial, gender and religious discrimination enacted by policies, environments, communities and even within households. As stated above, Somali patients have voiced perceived discrimination by mental health workers, which in and of itself is problematic (Wedel, 2011). It is not hard then to consider how these layered events of discrimination and disadvantage, may lead to vulnerability, meaning that it may impact mental health needs and care seeking behavior reciprocally (McLeroy, Bibeau, Steckler, & Glanz, 1988; Sweat & Denison, 1995). Concretely, a recent study of older women in the United States found that as intersectional discrimination experiences accumulated across time and across various intersectional attributes (gender, ethnicity, nativity, sexual orientation, weight, age, etc), the risk of depression rose (Bcares & Zhang, 2017).

2.5 Somali Mental Health & Service Use

Explanatory models surrounding mental health are frequently not aligned between Somali communities and Western healthcare. For example, there is the Somali term *Buufis*. This term was once used by Somali migrants to express their deep desire to one-day return home; a hopeful homesickness. Over the long years of resettlement this same word, *Buufis*, became marred with experiences of stress and poverty in the diaspora and came to signify instead an incurable sadness which has encompassed the lived experience of the Somali

people (JINNAH, 2016). As such, Somalis often understand depression as an incurable sadness, rather than a treatable disorder (Markova & Sandal, 2016). While Somalis acknowledge that social isolation, stressors such as unemployment, and history of trauma may cause poor mental health, additional explanatory models not supported by the US healthcare system include spirit possession by djinn, or the will of God (Bettmann, Penney, Clarkson Freeman, & Lecy, 2015; Johnsdotter, Östman, Ingvarsdotter, & Carlbom, 2011; Markova & Sandal, 2016; Pamela A. Clarkson Freeman MSW, Debra S. Penney CNM MS MPH, Joanna E. Bettmann LCSW, & Natalie Lecy, 2013; Scuglik, Alarcon, Lapeyre, Williams, & Logan, 2007; Wedel, 2011; Wolf et al., 2016).

Western treatment for mental illness is often considered a last resort for this population, due to fear of pharmaceutical side effects, discomfort with talk therapy, and low health literacy (Bettmann et al., 2015; Johnsdotter et al., 2011; Scuglik et al., 2007; Wedel, 2011; Wolf et al., 2016). Additionally, Somali mental health patients experience perceived discrimination by physicians, engendering distrust of health professionals (Wedel, 2011). Health literacy is poor among Somalis (Wångdahl, Lytsy, Mårtensson, & Westerling, 2014), and is associated with lower acculturation and delayed care seeking due to fear of the US medical system (Carroll et al., 2007). Treatments currently used within the community include reading the Qur'an, healthy diet and exercise, and mobilizing families to provide support (Betancourt et al., 2015; Bettmann et al., 2015; Johnsdotter et al., 2011; Pamela A. Clarkson Freeman MSW et al., 2013; Scuglik et al., 2007; Wedel, 2011; Wolf et al., 2016). This care occurs in the home, since mental disorders are often kept secret within families. Preferences towards alternative, traditional treatments may play a role in limiting immigrant health service utilization (Yang & Hwang, 2016). Stigma of being coined "crazy" in the

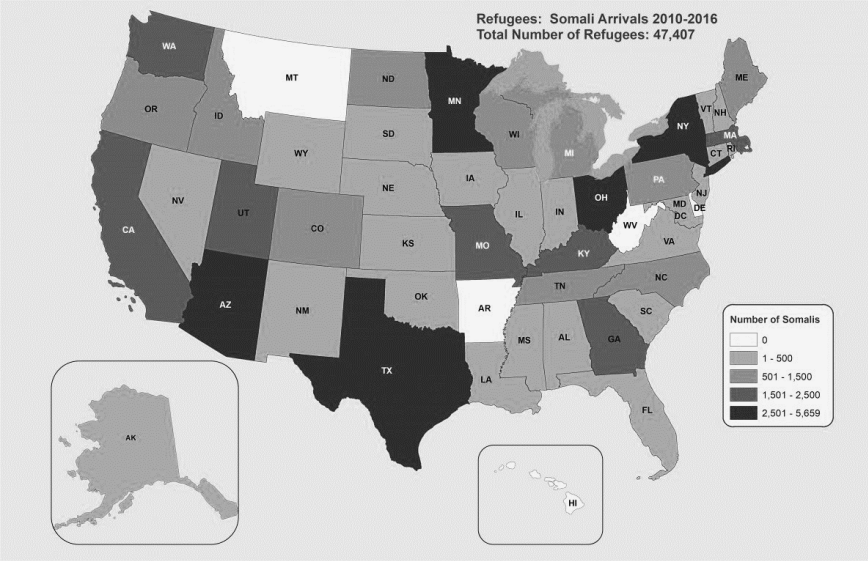
community is a significant fear for Somalis (Bettmann et al., 2015; Wedel, 2011; Wolf et al., 2016).

Somali women may not make mental health treatment decisions independently, behaving instead in alignment with community norms**.** Whether we envision these social actors as influencing women's behavior in the role of "gatekeepers" or simply as conduits of social pressure, parents, husbands, elders, and spiritual leaders, as well as other women, may set mental health priorities and influence decision making for this population (Markova & Sandal, 2016; Walick & Sullivan, 2015; Wolf et al., 2016). In order to increase service appropriateness and uptake, research with Somali adolescents suggested that targeting these individuals was a useful intervention strategy, and that future interventions in this culture should work within the natural hierarchy of the Somali community (Ellis & Lincoln, 2010; Scuglik et al., 2007). Through this analysis we proposed to move beyond dyadic relationships (parent/child, husband/wife, elder/youth), to instead understand how mental health and service use is influenced within the community, and through the community's response to the external US hegemony. Regardless, the necessity of community-based research approaches and innovative intervention strategies which respond not only to the objective needs of the Somali community and the evidence base of the scientific literature, but which are aligned with the community's social systems and understandings, is advised (B Heidi Ellis et al., 2016; Betancourt et al., 2015; Betancourt, Frounfelker, Mishra, Hussein, & Falzarano, 2015c; Ellis & Abdi, 2017).

2.6 Study setting

A. Study Location & Participants

Figure 5. Somali Arrivals by State 2010-2016 **(Centers for**



Arizona has been ranked in the top ten US states that receives Somali refugees for resettlement (Figure 5). This research was undertaken in the two major metropolitan areas of Phoenix and Tucson.

Participants were eligible for the quantitative questionnaire if they were 1) female, 2) self-identified as Ethnic Somali or Somali Bantu, 3) resided in Arizona in either the Phoenix or Tucson metropolitan area, and 4) were 15 years or older. For the qualitative sample men were also included, of the same ethnic, geographic and age range. Sampling was not based on FGM/C or immigration type or status.

Somalis are generally divided into ethnic Somali and Somali Bantu communities, both of which are represented in Arizona. The Somali Bantu people were the former slaves of Ethnic Somalis, and experienced decades of discrimination and marginalization within Somalia prior to refugee migration (Webersik, 2008). While it is difficult to enumerate precisely the percentage of the Arizona Somali population that is Bantu, gross estimates have concluded that the Bantu make up roughly 5% of the population in Somalia (Menkhaus, 2003). Furthermore, Somali Bantu refugees were prioritized in US resettlement policy as a minority persecuted group, resulting in a wave of approximately 12,000 Somali Bantu

refugee arrivals to the US in the early 2000s (Besteman, 2012). Both Bantu and Ethnic Somalis were included in all phases of this study in order to uncover significant differences between the groups. While conflict still exists between the Ethnic Somali and Somali Bantu communities, differences are potentially counteracted by similarities in trauma histories, refugee flight, migration, internal clan conflicts, acculturative stressors and experiences of poverty and discrimination in the US, as well as similarities in religious and familial coping and externalizing etiologies of mental health (Baker, 2007). On a methodological note, qualitative forums and focus groups were held separately for these ethnic subgroups, and quantitative findings were disaggregated to search for effects.

B. Parent Study Team

This project was nested in a 3 year community-based study funded by the DHHS Office on Women's Health meant to improve FGM/C-related health care services for women and girls in the US (WH-AST-16-002). Major contributors to the study included the Southwest Interdisciplinary Research Center of Arizona State University and the Refugee Women's Health Clinic (RWHC).

The RWHC opened in 2008 as a part of the Maricopa Integrated Health System (MIHS), a county hospital in Phoenix, Arizona. The RWHC's director and Principle Investigator for the parent study, Dr. Crista Johnson-Agbakwu, MD, has extensive prior research experience with the Somali community (Johnson-Agbakwu, Crista E., Helm, Killawi, & Padela, 2014; Johnson-Agbakwu, Crista E. et al., 2014; Lazar, Johnson-Agbakwu, Davis, & Shipp, 2013); she is also a nationally recognized content expert on FGM/C with nearly 20 years of experience related to the healthcare of Somali women in primary care and community-based settings. The RWHC has been recognized as a best practice model for refugee women's

health care in the US (AHRQ, 2014). RWHC staff are themselves bicultural and bilingual and represent diverse refugee communities. The RWHC operates largely using a community-based participatory research (CBPR) approach and functions in collaboration with the Refugee Women's Health Clinic Advisory Coalition (RWHCAC), an advisory board consisting of over 60 stakeholders from local ethnic community-based organizations, resettlement agencies, volunteer groups, academic partners and mental health and social service agencies. The use of CBPR in Somali refugee research and intervention planning has been considered both an ethically and methodologically rigorous technique (Ellis & Kia-Keating, 2007).

2.7 Contribution to public health

The current literature available suggests the following:

1) Somali women in the US are a vulnerable population with exposure to multiple factors associated with poor mental health;
2) While a current screener for refugee mental health exists and is widely used in the US among Somalis, evidence suggests that there is limited uptake of referrals for treatment, potentially due to either the invalidity of the screen, or resistance to US service use;
3) While prior evidence has suggested a link between FGM/C and mental health, the exact nature of that relationship is poorly explored;
4) Somali women in the US may have explanatory models and treatments for mental distress that are not accounted for within the US healthcare system;

And, 5) Somali women in the US may be constrained in their ability to seek mental health care due to myriad social factors internal and external to the Somali community.

This research contributes to overcoming the gaps in public mental health's ability to understand and address mental health in the US Somali community through:

1) Validation of a commonly used refugee health screener in order to increase confidence in the identification of women with clinically significant distress at primary care or other service locations;
2) Additional data on the predictors of clinically significant distress in this population, specifically regarding FGM/C, for which there is a dearth of current evidence;
And, 3) A better understanding of how socio-cultural factors both internal and external to the community specifically encourage or deter women from seeking mental health services after referral;

Through addressing these gaps in the current literature, future public mental health interventions may be more adequately tailored to the unique needs of Somali women. An important step in ensuring the success of future interventions to address mental health in this hard to reach, vulnerable population.

Chapter 3. Methods

3.1 Community-Based Participatory Research

This research was undertaken utilizing a community-based participatory research (CBPR) approach. The CBPR approach suggests partnership with the study population community and key stakeholders on many, if not all phases of research, from the beginning of research agenda setting to final dissemination (Balazs & Morello-Frosch, 2013). A review of scientific literature produced using CBPR techniques found that, particularly in the case of research with immigrant communities, CBPR collaboration improves not just the ethicality of research, but also its scientific rigor and endpoint impact (Vaughn, Jacquez, Lindquist-Grantz, Parsons, & Melink, 2017). CBPR has been used with prior success in Somali communities in the US, including in mental health research (Betancourt, Frounfelker, Mishra, Hussein, & Falzarano, 2015d; Johnson, Ali, & Shipp, 2009a).

Since the founding of the Refugee Women's Health Clinic (RWHC), it has partnered with its community-based advisory coalition the RWHCAC to set research agenda and disseminate findings. The RWHC and RWHCAC have partnered on several research projects related to refugee health and has established a strong research team grounded in community-based methodology. Beyond the ongoing collaboration with the coalition, the parent study for this thesis research received letters of support from the following Somali and refugee health community partners: Arizona Department of Health and Human Services, Maricopa Integrated Health Systems, University of Arizona, Catholic Charities, Refugee Focus, International Rescue Committee, Somali Bantu United Association of Greater Phoenix, Somali Community Development Center, Somali American United Council of Arizona and Hirsi Enterprises. These organization committed to make their

networks, expertise and personnel available (including faith-based leaders and community leaders within the Somali community).

The research study team worked closely with Somali community partners to refine the research agenda and develop instruments and tools, including the quantitative questionnaire. Members of the Somali community were hired as data collectors for both the quantitative and qualitative phases of the research, and a Somali women managed the data collection team in the second and third year of the parent project. Initial results of both the quantitative and qualitative aims of the parent project as well as this thesis work were disseminated to the Somali community in Arizona in June 2019 by way of a community data walk. A community data walk is a free community event organized by the research team. Our data walk exhibited the research processes, data and findings of the project in a series of sequential posters. Attendees included members of the community from which the study population was derived as well as key stakeholders such as the Phoenix city mayor. The goal of a data walk is not only to ensure research transparency and access to results, but also to promote the translation of academic research into programs and policies.

3.2 Sequential, Explanatory Mixed Methods

This study also utilized a sequential, explanatory mixed-methods design (Table 1) (QUANTITTATIVE->QUALITATIVE) to inform targeted mental health intervention development. Following the community-partnered development and administration of the Year 1 quantitative questionnaire, initial findings including percent of positive mental health screens were disseminated back to the study population in community forums in Year 2. Participants were then able to qualitatively discuss their perceptions of the results of the

survey in focus groups, adding qualitative depth and explanatory value to the quantitative results. In a review of over 100 mixed-methods approaches used in mental health research, this approach comprised only 20% of reported designs, but was found to be a superior method for needs assessments and service planning compared to other mixed methods designs (Palinkas, Horwitz, Chamberlain, Hurlburt, & Landsverk, 2011).

Table 1. Dissertation Methods Overview

Research Aim	Research Questions	Methods
Aim 1: Assess the validity of the Refugee Health Screener 13 among Somali women	(1) Does the RHS-13 appear valid in Somali women? (2) Does the currently recommended cut-off value of ≥11 appear valid? (3) Do positive screens associate in the anticipated directions with histories of trauma, poor physical health, and perceived discrimination? (4) What percent of the study population screens positive for clinically significant distress?	**Factor Analysis** of RHS-13 data • Comparison to factor loadings in other refugee groups **External Construct Validity** of RHS-13 data • Exploring correlation of positive screens to known associated variables **Use of Trauma Exposure as a criterion variable** to evaluate cut-off scores • ROC curve and sensitivity/specificity
Aim 2: Explore the relationship between FGM/C and clinically significant distress	(1) What are the major non-FGM/C-related predictors of positive screens? (2) Controlled for age, ethnicity, and other predictors, do any FGM/C-related variables associate with current distress?	**Descriptive Statistics** **Bivariate Logistic Regression** **Multiple Logistic Regression**
Aim 3: Identify how discourses around Somali mental health and service use encouraged or constrained the mental health	(1) What discourses exist in the community that inform, or impact service usage? (2) What subject positions (identities) are available to Somali women when deciding whether or not to disclose mental health status or seek mental health services?	**Discourse analysis** of qualitative data from focus group discussions with Somali men and women • Using semi-structured focus group guide

behavior or Somali women	(3) What sites of resistance exist which may explain Somali women's non-use of US mental health services?	

3.3 Defining and Measuring Mental Health

Mental health is understood and defined in this research according to World Health Organization guidance as a state of well-being where an individual is able to meet their potential, cope with the daily stresses of life, work productively and contribute to the community. This definition, markedly, does not underscore the presence or absence of any particular disorder. Most importantly, it sees mental health as influencing and being influenced by both physical and social well-being (WHO, 2014).

Common mental illness is understood as those disorders which occur with the greatest frequency in any given population. In the case of refugee populations, symptoms which are emblematic of anxiety, depression and post-traumatic stress are predictive of a clinically diagnosable disorder and indicative of psychological distress in need of treatment (Hollifield et al., 2013). Anxiety, or Generalized Anxiety Disorder, is a chronic condition where individuals experience worry and anxiety broadly in their lives in a debilitating fashion. It is characterized by poor sleep and concentration, irritability, fatigue and restlessness. Depression (depressed mood) is a state of mental illness which can be attributable to myriad of causes, including bereavement, demoralization, substance abuse and stressful life events, as well as clinical diagnoses such as major depression, bipolar, anxiety or personality disorder. The clinical diagnosis of Major Depressive Disorder is indicated by depressed mood alongside feeling uninterested in usual activities, changes in appetite and sleep patterns, feelings of worthlessness and thoughts of suicide. Post-Traumatic Stress Disorder (PTSD) is brought about by exposure to aversive life events, and results in symptoms such

as flashbacks, recurring memories or nightmares of the traumatic event, negative cognitions and mood, and angry outbursts (American Psychiatric Association, 2013).

Several lengthy and exhaustive quantitative instruments exist to measure each of these disorders individually; however, it is the goal of this research to be not only explanatory, but also practical and normative. The Refugee Health Screener 13 (RHS-13) is frequently used by state agencies, health services and volunteer, religious and community organizations as a way to quickly assess the mental health of refugees and immigrants of Somali origin (Appendix I). The RHS-13 identifies severe distress through item responses capturing the common symptoms associated with PTSD, anxiety and depression (Appendix I). If a screen is scored as positive, the woman will be provided with a referral to mental health care. As discussed previously, Somali women show relatively minimal uptake of services after referral (Johnson-Agbakwu, Crista E. et al., 2014), which may have to do with several factors related to their "willingness", and social and structural access to care.

The gold standard for the diagnosis of mental disorder in the US is through clinical interview utilizing the diagnostic criteria included in the Diagnostic and Statistical Manual of Mental Disorders, now in its 5th version (American Psychiatric Association, 2013). However, by using the RHS-13 as the data collection instrument for this research, this study proposes that while definitive biomedical evidence of disorder has its benefits, the on-the-ground identification of clinically significant distress among displaced, high-risk populations such as Somali women is generally assessed using a screener such as the RHS-13. Therefore, providing evidence towards its use and interpretation is a useful step towards improving mental health outcomes in real-world settings.

3.4 Exploring Vulnerability through Power and Discourse

In looking at vulnerability, we begin to see how it can exist as both an etiology for poor mental health as well as a barrier to care seeking for mental health services. The idea of vulnerability, as discussed in critical race theory, is an idea of relative difference; meaning that vulnerable positions are formed in response to power imbalances with dominant positions. Power can therefore be seen as the natural unit of analysis for studies of vulnerability.

Power was most notably defined and explored by Michel Foucault beginning in the 1960's. Foucault sought to define and understand power and, near the end of his life and career, defined it as the ways in which people are objectified and made into subjects. Foucault further posits that power objectifies individuals when they are marked as divided from others, or divided within themselves. Science and medicine is often complicit in this division. Power is therefore best analyzed at the divides; to look at points of opposition and resistance, and seek to better understand how and why such resistance is operating. Foucault specifically identifies, for instance, the opposition of the power of psychiatrists over the mentally ill (Foucault, 1982). Understanding this opposition (not only why the Somali woman might experience mental distress, but why the Somali woman might experience mental distress and refuse Western care) is important to public mental health practice. Similarly, understanding the reasons for opposition to care seeking may shed light on the etiology for poor mental health itself.

In order to analyze this situation, theorists have argued that one must look at social discourse. A definition of discourse grounded in social theory describes it as "a group of ideas or patterned way of thinking which can both be identified in textual and verbal communications and located in wider social structures" (Lupton, 1992). In other words, what we communicate to others, or have communicated to us, builds our understanding of

ourselves and the world around us and changes the way that we behave towards it. There are three aspects to this which are important to the use of discourse analysis: first, that discourse shapes our realities, second, that because of this, discourses exert power over us, and finally, that discourses exert power and shape realities based on dominant social structures (Lupton, 1992). In a review of vulnerability studies in the health literature conducted in 2013 it was found that none of the research included insights into the emic perspective of vulnerability; meaning that research did not describe the phenomena as it was perceived by the population of study. This was identified as the major gap in vulnerability health literature (Grabovschi et al., 2013). Expanding the study of vulnerability through the analysis of power and discourse, this research uses methodological tools uncommon to public health to attempt to address this gap.

Chapter 4. Properties of the Refugee Mental Health Screener (RHS-13) among Somali Women in the US State of Arizona

4.1 Abstract

Background

Pre- and post-migratory trauma and stress increase the risk for poor mental health among displaced refugees. Resettlement countries require efficient and appropriate mental health screening, hence the Refugee Health Screener is widely used to screen for distress. While a Somali-language version of the RHS is available, its validity among Somalis has not been explored.

Methods

Using factor analysis and comparisons with related constructs, we assessed its validity. History of trauma was used to estimate appropriateness of the recommended cutoff score.

Results

Data from 879 Somali women were used; approximately 15% scored above the cutoff, the majority (55%) with mild distress. Those screening positive most frequently reported thinking too much, and least frequently reported reliving a traumatic experience. Current distress strongly associated with poor physical health, perceived discrimination, and histories of trauma.

Conclusion

The RHS-13 appears valid for identifying clinically significant distress among Somali women aged 15+ with the currently recommended cutoff score.

4.2 Introduction

As of 2018, the United Nations High Commissioner on Refugees reported 25.9 million refugees worldwide, with 2.8 million people newly displaced as refugees in 2018 alone, and these numbers continue to rise (UNHCR, 2019). The country of Somalia, after decades of natural disaster and internal conflict, is the 5th highest sender of refugees in the world, creating a vast Somali global diaspora (Hammond, 2014; UNHCR, 2019). While the US ceased to accept Somali refugees after the 2017 Travel Ban and deportations of Somalis spiked (Gaffey, 2017; Trump, 2017a; Trump, 2017b), a large population of Somalis remain in the US (Connor & Krogstad, 2016), and the resettlement of Somali refugees continues in various countries both in Africa and the West (UNHCR, 2019).

Refugees in general, and Somalis in particular, are often exposed to multiple risk factors for poor mental health related to experiences of conflict or disaster, as well as difficulties during displacement and refugee migration, and finally post-migration stressors such as poverty, discrimination and acculturative stress (Bentley et al., 2012; Betancourt et al., 2015; Bhui et al., 2006; Ellis et al., 2008a; Ellis et al., 2010; Hulland, Miller, Bixby, Cardozo, & Betancourt, 2016; Kirmayer et al., 2011; Kroll, Yusuf, & Fujiwara, 2011; Wedel, 2011). Given the high risk for poor mental health among refugee groups, mental health screening is encouraged by institutions such as the Center for Disease Control in the U.S. upon arrival (US Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Emerging and Zoonotic Infections Disease, & Division of Global Migration and Quarantine, 2015). While refugees may not screen positive at their

first domestic exam, it is known that symptoms of post-traumatic stress disorder (PTSD) may take months or years to appear (Bremner, Southwick, Darnell, & Charney, 1996; Ehlers, Mayou, & Bryant, 1998; Wolfe, Erickson, Sharkansky, King, & King, 1999), and post-migratory stress may eventually lead to the emergence of disorders such as anxiety or depression (Aragona et al., 2013; Bentley et al., 2012), which suggests that repeated screening in primary care may be warranted.

In this context, valid screeners for clinically significant distress among refugee populations are essential. However, valid screens that are able to be used across multiple refugee groups with disparate cultural and linguistic backgrounds is a challenge. In order to overcome this challenge Hollifield et al created the Refugee Health Screener (RHS-15 & RHS-13) as an efficient option in primary care and other settings (Hollifield et al., 2013). However, given that the validity and utility of the RHS-13 is not guaranteed across cultures and contexts, in this study we analyze the instrument's validity among Somali migrant women in the US state of Arizona. While the RHS-13 is available in the Somali language, this research represents the first attempt to validate the screener within an exclusively Somali migrant population.

4.3 Methods

Recruitment

We recruited Somali women age 15+, Ethnic or Bantu Somali, currently residing in either Phoenix or Tucson, Arizona. Women were not excluded based on immigration status. Given that the Somali population in Arizona is not precisely enumerated and is historically difficult to access for large-scale research, a community-based approach was utilized (Ellis et

al., 2010; Spring et al., 2003). Twelve Somali community-based organizations and volunteer agencies providing refugee services collaborated with the study team at various stages to facilitate outreach and vet study instruments for cultural and contextual appropriateness. Respondent-driven sampling (RDS) was utilized in the first month of recruitment; however, after difficulty in later waves, snowball sampling was used. Surveys were administered by Somali women from the local community.

Procedure

Survey items were selected with input from researchers focused on Somali health as well as Somali community partners. Community Based Participatory Research was critical to our ability to garner and sustain community trust, buy-in, and mobilize the Somali community for this research, given that data collection coincided with the 2017 Travel Ban and deportations of Somalis from the US (Dahir, 2018; Trump, 2017a; Trump, 2017b). The English survey was translated and back translated into Somali and Maay Maay. Participants were interviewed by trained female Somali data collectors in a convenient location such as the home. Oral consent was obtained from participants prior to participation. Ethical approval for this study was obtained from Arizona State University. Interviews lasted between 1 and 3 hours and were completed in either English, Somali or Maay Maay, given the bilingualism of Somali data collectors.

Measures

Refugee Health Screener 13 (RHS-13)

The RHS-15 was created using the New Mexico Refugee Health Symptom Checklist (NMRSCL-121), a 121-item instrument shown to reliably and validly predict PTSD, anxiety and depression among Kurdish and Vietnamese refugees as the initial basis, also drawing on the Hopkins Symptom Checklist and the Posttraumatic Stress Disorder Symptom Scale Self

Report (Hollifield, Warner, Krakow, Jenkins, & Westermeyer, 2009; Hollifield et al., 2013). Items were chosen based on the strength of their association to diagnostic proxies for PTSD, anxiety, and depression, and post-hoc assessment and validation found that a 13-item screen (after removing an overall self-reported "thermometer" of distress and coping question from the RHS-15) showed this brief scale to quickly and effectively identify cases of PTSD, anxiety and depression in Iraqi, Burmese and Bhutanese refugees (Hollifield et al., 2016). The RHS-13 has been translated into 15 language using rigorous back-translation techniques and input from refugee native speakers (Appendix I) (Hollifield et al., 2013; Pathways to Wellness, 2011).

The Refugee Health Screener 13 (RHS-13) is commonly used to assess clinically significant distress in refugee populations in the US and other Western countries (Hollifield et al., 2013; Hollifield et al., 2016). The RHS, used by volunteer agencies in the states of Maryland, Utah and Washington, identifies poor mental health through a short (13-question; ~10 minute) scale (cutoff score ≥11) with items capturing anxiety, depression and PTSD symptomology. The total possible scale score is 52, standard cutoff is ≥11, and research of Iraqi, Burmese and Bhutanese refugee populations indicates good sensitivity (.82-.96) and specificity (.86-.91) to PSTD, Depression, and Anxiety (Hollifield et al., 2013; Hollifield et al., 2016). At this time, the primary refugee women's health clinic in Arizona, as well as other Arizona agencies, actively refer individuals positively screened using this instrument to mental health services.

Potentially Traumatic Experiences (PTE)

Consensus from the study team and community members was used to identify traumatic incidents most likely experienced by Somali migrant women; these included looting or burning of the home or other property, being abandoned by family, being

abducted, sexual violence, being attacked, and witnessing murder. Each item assessed whether the trauma had been experienced directly, or witnessed. Traumatic history was treated as a binary variable for the purposes of this analysis (experienced/witnessed any PTE, vs. none).

Perceived Discrimination

Two items were included on the survey to assess perceived discrimination. One queried whether the participant believed that immigrant and refugee women were looked down on/discriminated against by medical providers in the US. The other asked if, specifically, women with female genital mutilation/cutting (FGM/C) were discriminated against. These item responses were combined to report dichotomously any presence of perceived discrimination.

Self-rated Health

Individuals were asked to self-rate their current health on a Likert scale from Excellent (0) to Poor (4). Self-rated health, while varying based on age and culture, has been shown to be a significant independent predictor of mortality; with a relative risk for all-cause mortality of 1.23 for participants reporting "good", "fair", or "poor" health as opposed to "excellent"(DeSalvo, Bloser, Reynolds, He, & Muntner, 2006; Jylhä, 2009). Furthermore, this measure has been found to have good predictive validity, for instance among women in several Arab countries (Abdulrahim & Baker, 2009), as well as good reliability, reflected in good to excellent kappa scores (Lundberg & Manderbacka, 1996). Given that current evidence cautions that self-rated health may be modified by acculturation or age in the US, modifying effects were explored prior to multivariate analysis, and none were found (Finch, Hummer, Reindl, & Vega, 2002).

Acculturation

Acculturation was measured using the Modified Bicultural Involvement Questionnaire, adapted for use in US refugee populations (Appendix II) (Johnson-Agbakwu, Crista, Flynn, Asiedu, Hedberg, & Breitkopf, 2016; Szapocznik, Kurtines, & Fernandez, 1980). Two scales captured by the instruments assessing enculturation (the extent to which individuals participate in their traditional culture) and acculturation (the extent to which individuals participate in US culture) were used to discern four patterns of cultural involvement (PCI) aligning to dominant categories of acculturation theorized by the work of Berry[2]. The labels for some categories have been modified in order to accommodate more theoretically neutral language. The fiftieth percentile of each subscale was calculated to separate respondents into "high" or "low" on either scale. Individuals with high enculturation and low acculturation were categorized as practicing Traditional culture. Those with high acculturation and low enculturation were categorized Acculturated. Those with high scores on both scales were categorized Bicultural. Finally, those with low scores on both scales were categorized Hypocultural.

Statistical Methods

Statistical analyses were performed in STATA 14. In order to maintain the integrity of the screener, and given the brevity of the screen itself, individuals with missing data on the RHS-13 scale were excluded from analysis rather than performing an imputation procedure. Fifty-five participants (6% of the sample) skipped one out of the 13 RHS questions, and thirty-seven women (4% of the sample) skipped the mental health screener entirely. The sample size following the exclusion of participants with missing data was (n=761). While the appropriateness of the cutoff score was explored (described below), we

otherwise utilized the data from the RHS-13 as a dichotomous variable taken as a summary score either above or below the cutoff value.

The validity of the RHS-13 Refugee Health Screener was analyzed through confirmatory factor analysis and through assessing its external construct validity based on the presence of associations to known related constructs. A polychoric correlation matrix was used for factor analysis given that the RHS-13 uses likert scale, ordinal responses. Principle component analysis and parallel analysis informed the final factor solution. We used maximum likelihood to fit the model. The results of the factor analysis in this study population was compared to analyses of the RHS-13 in previously studied populations. This includes whether or not a similar number of factors were identified, factor loading values, and the overall percent variance explained by each factor. For external construct validity, all variables were first explored descriptively. Bivariate associations were then examined to determine if the relationships between expected predictors and clinically significant distress were significant in the expected directions.

Clinical diagnosis information was not collected as part of this study, so there was no diagnostic Gold Standard for criterion validity; however, given that post-hoc analysis found trauma history to be significantly associated with positive screens with a large effect size, trauma history as a binary variable (present or not) was used as a criterion to assess the sensitivity and specificity of the screen (Altman & Bland, 1994). Cutoff values between 9 and 16 were explored. The sensitivity and specificity values generated by each cutoff value were then compared to sensitivity and specificity reported for the RHS-13 in validation studies which used psychiatric diagnosis as the gold standard (Hollifield et al., 2016).

Finally, using the suggested cutoff score (Hollifield et al., 2016), we report the percent of positive screens in the study population. Average item responses were explored

descriptively in order to explore the relevance of particular distress experiences as collected by the RHS-13 in the study population. Severity of symptoms was stratified as mild (≥11), moderate (≥18) and acute (≥25) according to cutoffs suggested by prior research (Bjärtå, Leiler, Ekdahl, & Wasteson, 2018a).

4.4 Results

Nearly three quarters of the sample were Ethnic Somali, with the remainder representing the Somali Bantu subgroup (Table 1). Similarly, the majority of participants (69.5%) were born in Somalia, with 19% born in Kenya. A very small proportion (5.2%) were born in the US or another Western country. Many (36.1%) reported strong preferences for American culture (acculturated), though a nearly equal amount (33.3%) strongly preferred their culture of heritage (traditional), the remainder being either bicultural (12.1%), or showing limited involvement in either culture (hypocultural, 18.5%) (Berry, 1997). Household sizes were quite large (38.8% 6+ persons); however, household incomes were generally <25,000 USD per year.

The average RHS-13 score was 3.7 (SD 6.98) (out of a possible 52), with total summed scores ranging from 0 to 44. Item responses ranged from "Not At All" (0) to "Extremely" (4), based on how much a particular symptom had been bothersome to that individual over the last month. Item response averages ranged from 0.22 to 0.57 (range 0-4) (Table 2). Among those screening positive for clinically significant distress using the recommended cutoff of ≥11 (Hollifield et al., 2016), the highest average item response was for "too much thinking/having too many thoughts" (M 1.98). The lowest was for the experience of reliving a traumatic experience, acting or feeling as if it were happening again

(M 1.10). In this study's data the RHS-13 demonstrated high internal reliability (Cronbach's α = 0.92).

Women reported potentially traumatic experiences across the various items. The most widely experienced trauma (directly or vicariously) was the looting or burning of the home or other property, with the least likely being abduction (Figure 6). The experience of multiple traumatic events throughout a woman's history was also not uncommon, with nearly 10% experiencing multiple traumas throughout their life histories (Table 3).

When asked whether the participant thought that refugee or immigrant women were discriminated against in the U.S. 133 women (15.7%) responded affirmatively. Similarly, when asked whether women with FGM/C were discriminated against 136 women (16.1%) responded yes. One hundred and three women (12.2%) responded yes to both questions.

When self-rating their overall health 463 (53.4%) of women responded that their health was excellent, 209 (24.1%) very good, 146 (16.8%) good, 43 (5%) fair, and 6 (0.7%) poor.

Prior research suggests that psychological distress is associated with history of trauma, post-migration living difficulties such as discrimination, and poor physical health. Bivariate analysis showed that each of these measurements associate with a positive screen using the RHS-13. As expected, positive screening for clinically significant distress via the RHS-13 was associated in bivariate analysis with history of trauma, cumulative trauma history, perceived discrimination, and self-rated health (Table 4).

Factor Analysis

Principle component analysis returned the first and second components of the RHS at eigenvalues of 9.83 (explaining 75.6% of the variance) and 0.98 (explaining 7.4% of the variance), respectively. These two components taken together explained 83% of the variance.

A scree plot of eigenvalues after principle component analysis as well as parallel analysis suggested a 1 or 2 factor solution. After examining the communalities for coherence as well as taking into account the EV of the second factor under the recommended cutoff value of one, a final factor solution of one was determined. The results of the factor analysis, an overview of factor loadings, alongside the factor results from the original validation study are presented in Table 5.

Trauma History as a Discriminator of Cutoff Value Appropriateness

In the original validation study by Hollifield et al (2016) PTSD, anxiety and depression proxy diagnoses were used as validation gold standards against which an ROC curve was mapped to determine the optimal cutoff score. Table 6 displays these sensitivity and specificity values compared to the values returned using histories of trauma (yes/no) as a discriminator for distress. The area under the curve for trauma as a discriminator was 0.82.

Similar to the results for the original RHS-13 validation (Hollifield et al., 2016), trauma as a discriminator suggested that a cutoff value of 11 or higher in this population operates with high specificity (94.9%) while higher values might cost steep declines in sensitivity. The specificity of the discriminator remains high, given that the RHS-13 appears to be able to easily identify women without histories of trauma. However, the sensitivity of the discriminator is quite a bit poorer than diagnostic proxies from the original study (Hollifield et al., 2016) given its inability to discriminate between women who will experience trauma and develop mental disorder and those who will not. With a sensitivity of roughly 50% of every 100 women with histories of trauma, 50% of them will be correctly identified by the screen.

Percent positive screens

RHS-13 screens with any items missing were dropped from analysis. In the remaining sample of 761 Somali women 15.51% (n=118) screened positive for clinically significant distress. Of these, 55% registered with mild symptoms (n=65), 31% moderate (n=37), and 14% acute (n=16).

4.5 Discussion

In assessing the validity of the RHS-13 among Somali migrant women in the state of Arizona, approximately 15% of the study population screened positive for clinically significant distress, and the majority (55%) with mild distress. The average cumulative score on the screener was low (3.7/52), with those screening positive most frequently reporting thinking too much, and least frequently reporting reliving a traumatic experience. External construct validity found positive screens to be associated with histories of trauma, perceived post-migration discrimination, and self-rated health in the expected directions. Factor analysis loaded all scale items onto a single factor explaining 75.6% of the variance, and the cut off score of ≥11 appears appropriate in this population.

The validation of this instrument agrees with prior studies in multiple groups, though there have been a few contextual concerns. Beyond validation in Iraqi, Burmese and Bhutanese refugees to the US which occurred during the original creation and assessment of the instrument (Hollifield et al., 2013; Hollifield et al., 2016), a study in Germany found the RHS-15 to be valid for use in a multi-ethnic sample of refugees, the majority of whom were Syrian (Kaltenbach, Härdtner, Hermenau, Schauer, & Elbert, 2017). A Swedish study found the RHS-13 to be valid among a refugee sample mostly from Afghanistan, Syria, and Iraq (Bjärtå et al., 2018a). The Spanish version of the instrument has also been validated among

Cuban refugees (Bosson et al., 2017). Regarding the assessment of the appropriateness of the screen based on the context of its use, a study of Burmese-speaking and Sgaw Karen-speaking migrant women along the Burma-Myanmar border found that while the psychometric properties of the RHS-15 appeared good, that women in this setting struggled with the Likert Scale questions, making it unfit for perinatal depression screening in this population (Fellmeth et al., 2018). This concern was not found in our participants.

The percentage of positive screens may appear low in this population, given that estimates of distress via positive RHS screening have indicated higher frequencies among other refugee groups (Nepali 28%, Iraqi 50.5%), though Burmese refugees screened at 10.8%, lower than our population (Hollifield et al., 2013). In a study of refugees in Finland of primarily Afghani and Syrian origin the mean score on the RHS-13 was 22.9 (SD 13.5) with an overall frequency of positive screens of 77%, considerably higher than in our population; however, this study was conducted among incoming refugees many of whom were still awaiting decisions regarding their immigration status, which may account for the higher rates of distress (Bjärtå, Leiler, Ekdahl, & Wasteson, 2018b). Estimates of PTSD among Somali refugees living in a Ugandan camp found that 48% had significant symptoms using the Posttraumatic Diagnostic Scale (Onyut et al., 2009). Estimates using the RHS-15 among Cuban refugees found rates of 17.6%, comparable to this study's findings (Bosson et al., 2017). In a clinical sample of Iraqi, Burmese and Somali refugees in Arizona, the site of this research, 3 out of 22 Somali women screened with the RHS-15 were positive (13.6%)(Johnson-Agbakwu, Crista E. et al., 2014).

Given that this is a community based sample, including women from diverse migratory backgrounds, including not only relatively new refugee arrivals as well as those with decades lived in the US and US born second-generation Somalis, it is possible that this

particular community's levels of distress have settled to reflect the prevalence one might anticipate in the US at large. The US National Comorbidity Survey found the 12-month prevalence for anxiety disorders to be 18.1%, and 9.5% for mood disorders; of these cases, 22.3% were classified as acute; 37.3%, moderate; and 40.4%, mild (Kessler, Chiu, Demler, & Walters, 2005), similar to the spread of symptom severity found in this sample. While a study of Somali migrants in Finland found that psychological distress had a point prevalence far higher in Somalis than the surrounding Finnish community as measured by the General Health Questionnaire-12, frequency of depression was not significantly different between the migrant Somali (21.1%) and native Finnish communities (14.1%) as measured by the Becks Depression Inventory (Mölsä et al., 2014). It is also possible that, due to severe stigmatization against mental health in the Somali community (Scuglik et al., 2007), and given that members of the Somali community were used as interviewers, mental health symptoms were underreported. However, a prior study of Somalis in Minnesota found that while mental health stigma was high in the Somali community compared to the surrounding US community, that stigma was not associated with self-reported mental health (Henning-Smith, Shippee, McAlpine, Hardeman, & Farah, 2013).

History of trauma, poor physical health, and perceived discrimination were used in this analysis to confirm external construct validity given the breadth of literature linking these experiences to poor mental health (Ellis et al., 2008a; Jylhä, 2009). While this research presents the first view of self-rated health among a Somali migrant population in the U.S., previous studies of migrant self-rated health in Canada found that 12.3% of migrant women reported fair or poor health, more than double the 5.7% found in the U.S. Somali population assessed in this study, suggesting that it is a relatively healthy migrant community in North America (Newbold, 2005). While caution is necessary regarding the potential of SES as an

effect modifier, (Regidor, Guallar-Castillon, Gutierrez-Fisac, Banegas, & Rodriguez-Artalejo, 2010) given the homogenous low socioeconomic status of this population, this was not a major concern in our study.

Factor solutions for the RHS-13 have varied by population; however, the one-factor solution for the Somali population (1 factor, 75.6% variance, EV 9.8, communalities ranging .84 to .54) is comparable to that found in Iraqi refugees (1 factor, 69.4% variance, EV 9.0, communalities ranging .81 to .58.)(Hollifield et al., 2013). The identification of one underlying factor in brief screeners for distress is common, as in the case of the General Health Questionnaire (GHQ-12)(Romppel, Braehler, Roth, & Glaesmer, 2013). The multifactorial solution for Burmese refugees using the RHS-13 (Hollifield et al., 2016) has also arisen with the GHQ-12 in particular study populations, such as Angolan and Saudi Arabian (El-Metwally et al., 2018; Tomás, Gutiérrez, & Sancho, 2015); however, this was not the case in our study population. Importantly, this study suggests that the currently recommended cutoff score (≥11) is appropriate, in spite of suggestions that the cutoff be raised (≥13) based on validation in a mixed sample of refugees in Germany (Kaltenbach et al., 2017).

The primary limitation of this study is the lack of a clinical interview for use in criterion validity. Furthermore, a more comprehensive instrument assessing discrimination, rather than the single item used, would have strengthened confidence in the association between perceived discrimination and positive screens. Despite these limitations, the use of community-based participatory research methods permitted data collection during a time of duress in the US Somali community. Longitudinal follow up with participants from this study, to be collected in 2019, offers the potential for additional insights into distress within this population.

Conclusion

This validation of the RHS-13 among Somalis in the US is an important step to not only ensuring the utility of this efficient and ubiquitous screening instrument, but also towards understanding the burden of distress in a Somali community in the US. While distress is lower in this community-based sample than in many refugee-only samples, there is still a clear and urgent need for mental health services for this population. Given the high level of mental health stigma in the Somali community (Henning-Smith et al., 2013; Scuglik et al., 2007), and considering other barriers to care experienced by migrant groups (Yang & Hwang, 2016), adequately identifying individuals in need of further diagnosis and intervention is important for care.

4.6 Tables for Chapter 4

Table 2. Sample Characteristics of participating Somali Women (N = 879), Chapter 4

Characteristic	%	n	M	SD	Range
Age (years)			31.15	13.8	15-90
15-17	12.8	110			
18-25	30.6	263			
26-45	41.1	353			
46-60	11.1	95			
61+	4.5	39			
Marital Status					
Single	42.3	366			
Married	41.9	362			
Divorced/Separated	8.2	71			
Widowed	7.5	65			
Ethnicity					
Ethnic Somali	73.7	631			
Somali Bantu	26.3	225			
Country of birth					
Somalia	69.5	585			
Kenya	19.0	160			
Other Africa/Middle	6.3	53			
East	5.2	44			
US/Europe					
Lived in refugee camp					
No	32.2	197			
Yes	67.8	415			
Years spent in refugee			10.36	6.44	0-30
camp					
Immigrant Arrival					
Refugee/Asylee	78.3	611			
Other*	16.0	125			
U.S. Born	5.6	44			
Age of arrival in the U.S.			24.86	17.33	1-88
(years)	21.5	179			
0-12	14.6	121			
13-17	34.5	287			
18-29	19.3	160			
30-45	10.1	84			
46+					
Years in the U.S.			8.67	6.85	0-47
Acculturation strategy					
Bicultural	12.1	106			
Acculturated	36.1	316			
Traditional	33.3	291			
Hypocultural	18.5	162			

Arizona Metropolitan Area	78.1	644
Phoenix	21.9	181
Tucson		
Household size		
1	8.3	71
2	13.6	116
3-5	39.3	335
6+	38.8	331
Annual Household Income	41.4	247
< 10,000 USD	38.8	231
10 – 24,999 USD	19.8	106
>25,000 USD		
FGM/C Type		
Uncircumcised	24.8	199
Type I (Sunna)	27.7	223
Type II (Excision)	17.3	139
Type III (Infibulation)	30.2	243

*Includes immigration for the purposes of family reunification, economic or educational development, or other non-refugee/asylee purposes

Table 3. Refugee Health Screener Item Responses

	%	n	M	SD
Overall Score			3.7	6.98
Screening Results*				
Negative	84.5	643		
Positive	15.5	118		
Muscle, bone, joint pains				
Overall			0.57	1.06
Positive Screens			1.43	1.45
Feeling down, sad, or blue				
Overall			0.31	0.77
Positive Screens			1.61	1.08
Too much thinking/too many thoughts			0.47	0.99
Overall			1.98	1.23
Positive Screens				
Feeling helpless				
Overall			0.33	0.81
Positive Screens			1.50	1.08
Suddenly scared for no reason				
Overall			0.24	0.67
Positive Screens			1.40	1.09
Faintness, dizziness, or weakness			0.30	0.72
Overall			1.50	0.98
Positive Screens				
Nervousness or shakiness inside				
Overall			0.23	0.67

Positive Screens	1.27	1.09
Feeling restless, can't sit still		
Overall	0.24	0.68
Positive Screens	1.31	1.10
Crying easily		
Overall	0.28	0.73
Positive Screens	1.42	1.12
Reliving trauma		
Overall	0.22	0.65
Positive Screens	1.10	1.14
Physical reactions when reminded of the trauma		
Overall	0.23	0.64
Positive Screens	1.25	1.03
Felt emotionally numb		
Overall	0.24	0.68
Positive Screens	1.25	1.14
Been jumpier, more easily startled	0.26	0.71
Overall	1.24	1.11
Positive Screens		

* Cutoff ≥ 11

Figure 6. Frequency of lifetime potentially traumatic experiences

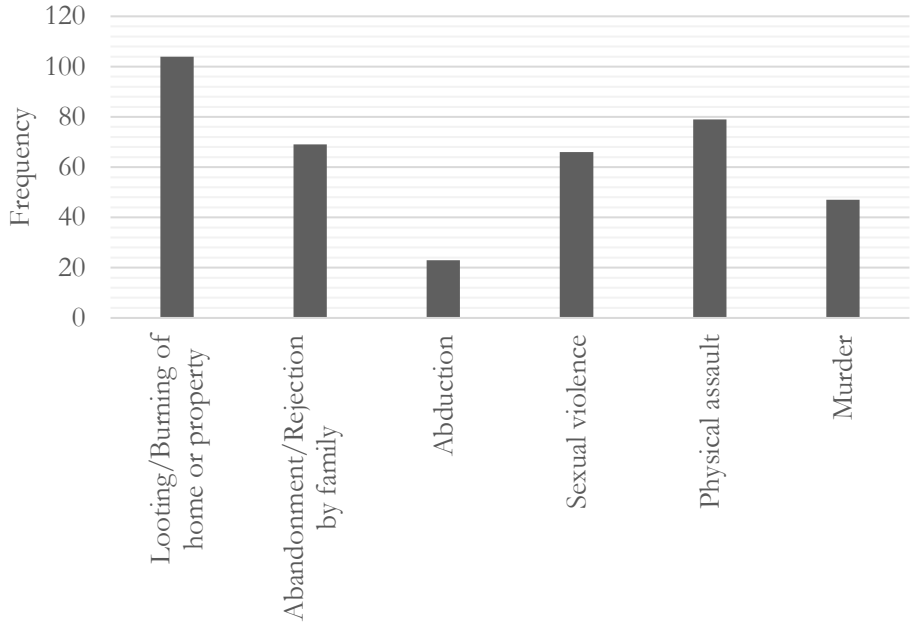


Table 4. Cumulative Lifetime Trauma History

Number of events	n	%
0	685	77.93
1	113	12.86
2	28	3.19
3	22	2.5
4	10	1.14
5	13	1.48
6	8	.91

Table 5. Bivariate associations with distress indicated by the Refugee Health Screener (N=761)

	RHS negative N (%)		RHS positive N (%)		Odds ratio (95% CI)
Trauma History (yes/no)	85 (13.22)		88 (74.58)		**19.26 (12.00-30.90)**
Are refugee/immigrant women discriminated against? (yes/no)	75 (11.98)		43 (36.75)		**4.27 (2.73-6.67)**
Are women with female genital cutting discriminated against? (yes/no)	79 (12.6)		3 (36.75)		**4.03 (2.59-6.28)**
	M	SD	M	SD	
In general, how would you say your health is? (1 (excellent)-5(poor))	1.62	0.88	2.32	0.98	**2.05 (1.68-2.49)**
Cumulative trauma history (0-6)	0.28	0.90	1.42	1.50	**1.98 (1.68-2.32)**

Table 6. Factor Analysis Results and Comparisons to Previous Studies*

Population	Factor Components	Eigenvalues	Percent Variance Explained	Factor Loadings
Somali women (n=761)	1	9.83	75.6%	
Muscle, bone, joint pains				0.54
Feeling down, sad, or blue				0.90
Too much thinking				0.85
Feeling helpless				0.89
Suddenly scared				0.93
Faintness, dizziness, weak				0.88
Nervousness or shakiness				0.91
Feeling restless				0.90
Crying easily				0.91
Reliving trauma				0.82
Physical reactions to memory				0.87
Emotionally numb				0.88
Jumpier, easily startled				0.84
Iraqi (n=60)	1	9.3	71.6%	0.58-0.87
Bhutanese (n=63)	1 or 2	8.7, 1	66.8%, 7.8%	0.61-0.85
Burmese (n=55)**	4	4.1, 1.8, 1.4, 1.2	31.2%, 13.9%, 10.8%, 9.3%	0.47-0.78

*(Hollifield et al., 2016)

** Factor analysis was difficult to interpret in the case of the Burmese data given that items did not clearly load onto factors both when rotated and unrotated.

Table 7. Sensitivity and Specificity at Various Cutoff Scores of the Refugee Health Screener (N=761)

		9	10	11***	12	13	14	15	16
History of Trauma (yes/no)*	Sensitivity	0.532	0.532	0.509	0.480	0.439	0.364	0.347	0.295
	Specificity	0.939	0.944	0.949	0.951	0.959	0.968	0.968	0.969
PTSD**	Sensitivity	0.881	0.851	0.821	0.821	0.761	0.746	0.746	0.702
	Specificity	0.859	0.887	0.906	0.915	0.915	0.943	0.953	0.972
Anxiety**	Sensitivity	1.000	1.000	0.960	0.940	0.880	0.880	0.880	0.840
	Specificity	0.805	0.846	0.862	0.862	0.870	0.902	0.911	0.935
Depression**	Sensitivity	0.964	0.946	0.911	0.893	0.857	0.857	0.857	0.804
	Specificity	0.859	0.887	0.906	0.915	0.915	0.943	0.953	0.972

*Original data set of Somali women in Arizona, n=761

** PTSD, anxiety and major depression proxy diagnoses as reported in Hollifield et al, 2016

*** Current recommended cutoff value for RHS-13

Chapter 5. Female Genital Mutilation/Cutting and Psychological Distress among Somali Women in the United States

5.1 Abstract

Background

In Western contexts, few studies have explored the relationship between female genital mutilation/cutting (FGM/C), stressors related to FGM/C, and mental health in combination. To provide adequate and appropriate services for women who have experienced FGM/C, understanding these relationships is warranted. The objective of this analysis was to examine how FGM/C and associated stressors are related to mental health outcomes among Somali immigrant women living in Arizona.

Methods

Data collection for this cross-sectional study took place in 2017 as part of a three-year, multi-armed study to improve health services for women with FGM/C in the state of Arizona. Participants were female ethnic Bantu or Bantu Somali women, age ≥15 residing in Arizona. We identified participants using respondent-driven and snowball sampling. Six percent of the sample was excluded from analysis due to lack of response on mental health questions. The Refugee Health Screener (RHS-13) was used to assess clinically significant distress.

Results

Study participants (N=879) were majority ethnic Somali (n=631) with an average age of 31 years. Over seventy-seven percent of women reported FGM/C (n=680), most commonly the most severe Type III (n=243). Approximately sixteen percent met the RHS-13 cut-off

criteria for clinically significant distress (n=118). Although there was no clear association between FGM/C and distress in multivariable analyses, adjusted models among women with FGM/C (n=459) showed that women who reported adverse experiences related to FGM/C were more likely to meet cut-off criteria for clinically significant distress (OR=4.29;95%CI 1.68-10.97). Other potentially traumatic experiences (OR=8.94;95%CI 3.81-20.98) and perceived discrimination (OR=2.90;95%CI 1.20-7.02) were also associated with clinically significant distress.

Conclusion

Findings suggest that the impact of FGM/C on women's mental health may be sensitive to other salient experiences and factors that in combination may differentially affect mental health status. The experience of FGM/C continues to impact the current health of some women, particularly those for whom there were adverse experiences.

5.2 Introduction

Female Genital Mutilation and Cutting (FGM/C), sometimes referred to as female circumcision, is practiced in over 30 countries in Africa, Asia and the Middle East(UNICEF, 2019; World Health Organization, 2016; Yoder, Abderrahim, & Zhuzhuni, 2004). The World Health Organization (WHO) defines FGM/C as all procedures involving the partial or total removal of female genitalia, including any modifications for non-medical reasons.(World Health Organization, 2016) This definition encompasses an array of practices worldwide with variation in cultural and religious construction as well as procedural severity(Shell-Duncan & Hernlund, 2000; Yoder & Khan, 2008).

Large refugee migrations of women who have experienced FGM/C to Western countries have drawn attention to the practice and made the medical and psychological sequelae of FGM/C of particular interest and importance to Western healthcare providers. These include obstetric risks such as postpartum hemorrhage or prolonged labor, sexual functioning risks like dyspareunia, or other long-term risks like chronic genital infections, or pelvic pain(Berg, Denison, & Fretheim, 2010a; Berg, Underland, Odgaard-Jensen, Fretheim, & Vist, 2014; Klein, Helzner, Shayowitz, Kohlhoff, & Smith-Norowitz, 2018; World Health Organization, 2016).

While the negative obstetric and gynecological consequences of FGM/C are well documented(Berg et al., 2010a; Berg et al., 2014; Klein et al., 2018), the relationship between FGM/C and mental health has been a subject of ongoing debate(Mulongo, Hollins Martin, & McAndrew, 2014). Furthermore, while many refugees experience multiple risk factors for poor mental health, including traumatic experiences from war and migration, as well as post-migratory difficulties such as poverty, discrimination, and acculturative stress(Aragona et al., 2013; Bentley et al., 2012; Bogic, Njoku, & Priebe, 2015; Ellis, MacDonald, Lincoln, & Cabral, 2008b; Ellis et al., 2010; Fazel, Wheeler, & Danesh, 2005; Kirmayer et al., 2011; Steel et al., 2009), there is a general paucity of research on the relationship specifically between FGM/C and distress among refugee women.

Support for this association has been inconsistent across contexts, sometimes showing a significant association between FGM/C and increased distress(Ahmed et al., 2017; Behrendt & Moritz, 2005b; Elnashar & Abdelhady, 2007; Kizilhan, 2011; Knipscheer, Vloeberghs, van der Kwaak, & van den Muijsenbergh, 2015; Vloeberghs, Van der Kwaak, Knipscheer, & van den Muijsenbergh, 2012), and other times not(Applebaum, Cohen, Matar, Rabia, & Kaplan, 2008; Chu & Akinsulure-Smith, 2016; Daneshkhah, Allahverdipour,

Jahangiri, & Andreeva, 2017). Studies have been primarily cross-sectional and vary in psychological measurement and most have assessed FGM/C as a single binary variable. However, context may play an important role, and some early researchers posited that in communities practicing FGM/C psychological harm might be minimal, given social norms and the possibility that uncircumcised girls might face "disapproval and derision"(Black & Debelle, 1995). Two literature reviews of FGM/C and psychological outcomes called for more nuanced research, including information about types and experiences surrounding the circumcision itself, to enrich our understanding of this complex relationship(Berg, Denison, & Fretheim, 2010b; Mulongo et al., 2014).

In the U.S., one FGM/C-affected diasporic population are Somalis. As of 2016, there were approximately 150,000 foreign-born Somalis in the US(Connor & Krogstad, 2016). Somali migrants have experienced myriad risk factors for poor mental health since displacement began in the early 1990s(Baker, 2007; Bentley et al., 2012; Bhui et al., 2006; Ellis et al., 2008a; Hammond, 2014; Hulland et al., 2016; Kroll et al., 2011; Lincoln et al., 2016; McCrone et al., 2005; Nilsson, Brown, Russell, & Khamphakdy-Brown, 2008; Warfa et al., 2006; Wedel, 2011; Whittaker, Hardy, Lewis, & Buchan, 2005). According to the United Nations Children's Fund Multiple Indicator Cluster Survey in 2006, FGM/C in Somali was nearly universal, and of the three types of FGM/C, roughly 75% reported Type III (Pharaonic) infibulation, the most severe form(Population Reference Bureau, 2017; World Health Organization, 2016).

In this study we examined how FGM/C and FGM/C-related stressors were related to current clinically significant distress among Somali women living in the U.S. This analysis offers primary healthcare providers, mental health specialists, and other service providers,

insights into the role of FGM/C and other salient factors on women's mental health in the U.S. context.

5.3 Methods

Participants and Procedures

Participants included a community-based sample of 879 Somali women aged 15 and older recruited in Arizona as part of a study to improve health services for women with FGM/C, funded by the Department of Health and Human Services Office on Women's Health (WH-AST-16-002). This study used respondent-driven and snowball sampling to recruit participants(Ellis et al., 2010; Spring et al., 2003). Twelve organizations representing Somali community-based organizations as well as refugee volunteer agencies collaborated with the study team to sensitize the community to research efforts and promote outreach.

The study questionnaire was created through input from an expert panel of scholars with over 50 years of combined health-related experience in Somali communities, and in collaboration with Somali community partners. The questionnaire items were translated and back translated for accuracy from English into two commonly spoken languages in the Somali community: Somali and Maay Maay.

Community mobilizers were Somali women trained in study recruitment and survey administration. Community mobilizers verbally administered the questionnaire in participants' homes, or another agreeable place. Ethical approval for the parent study was obtained from Arizona State University's Institutional Review Board, and verbal consent was obtained from participants prior to participation. Interviews lasted an average of one hour, varying based on the extent of medical history reported.

Measures

FGM/C Status & Type

Data on type of FGM/C were collected using the RAINBO© illustrated guide(Toubia, 1999), which has been used successfully with Somali women and is believed to increase the validity of their self-report(Johnson, Ali, & Shipp, 2009b). FGM/C pictorial imagery was embedded in tablets used for survey administration. Possible responses included Type I (Sunna), Type II (Excision), Type III (Pharaonic Infibulation), and an option of no FGM/C. Table 8 provides additional details on how FGM/C types were operationalized.

Other FGM/C-related Variables

Data were collected on age of FGM/C, advanced knowledge and choice to undergo FGM/C and recall of any adverse physical or psychological reactions at the time of or immediately following the FGM/C. The adverse reactions included: extreme pain, excessive bleeding, psychological shock, infection, pain or difficulty urinating, or a long or difficult recovery. Because some women may have undergone multiple FGM/C events, women were asked how many times they had experienced FGM/C.

One categorical item asked women to report on their beliefs about FGM/C; specifically, women were asked if they thought FGM/C should: a) stop, b) continue traditionally, c) only be allowed among consenting adult women or, d) if the Pharaonic form (Type III) should stop, but the Sunna form (Type I) should continue traditionally. Women who checked multiple boxes were excluded from categorical analysis but were analyzed separately to see if holding multiple views simultaneously was associated with distress.

Refugee Health Screener 13 (RHS-13)

To assess distress, the RHS-13, an abbreviated version of the Refugee Health Screener 15 (RHS-15), was used (Appendix I). Both versions are frequently used to screen for distress among refugees in the US and are available in Somali. The instrument identifies distress through a brief (13-question; ~10 minute) scale with items assessing symptoms associated with anxiety, depression and PTSD. Previous validation studies in refugee populations have found the RHS-13 to be an effective assessment of clinically significant distress predictive of PTSD, generalized anxiety disorder and depression(Hollifield et al., 2013; Hollifield et al., 2016). Using a standard cutoff score ≥11, studies among Iraqi, Burmese and Bhutanese refugees have found good sensitivity (.82-.96) and specificity (.86-.91), with negligible between-group differences(Hollifield et al., 2013; Hollifield et al., 2016). In a separate validity analysis in this population of Somali refugees, we found a cutoff value score of 11 to be appropriate.(Michlig, Johnson-Agbakwu, Surkan, Hollifield, & Bass, 2019) For this study, individual scores on the RHS-13 were summed and analyzed as a binary variable indicating clinically significant distress (i.e. above vs. below cutoff value).

In order to maintain the integrity of the screener, and given the brevity of the measure, individuals with any missing data on the RHS-13 scale were excluded from the analysis, rather than performing an imputation procedure. Fifty-five participants (6% of the sample) skipped one of the RHS-13 questions, and thirty-seven women (4% of the sample) skipped the RHS-13 screener entirely. The sample size following the exclusion of participants with missing data was 761.

Potentially Traumatic Experiences and Discrimination

During questionnaire development, expert consensus was used to identify potentially traumatic incidents most likely to have been experienced along a Somali woman's migratory pathway. Items assessed whether the trauma was experienced directly, or witnessed, and

included looting or burning of the home or other property, being abandoned by family, being abducted, sexual violence, being attacked, and witnessing murder. For the purposes of this analysis, past trauma history was analyzed as a binary variable, having experienced directly or witnessed any of these events or not, given that the effect size of even a single traumatic event was large.

One dichotomous item (yes/no) was used to assess perceived discrimination against women with FGM/C, asking whether the participant believed that women with FGM/C are discriminated against by healthcare providers.

Statistical Methods

Descriptive statistics included bivariate analyses of associations between demographic and FGM/C factors with the binary indicator of clinically significant distress using logistic regression. Multivariable logistic modeling was used to further explore contributing factors. In all analyses, age and ethnicity were controlled for based on the theoretical assumption that both variables might have separate relationships with the exposures and the outcome that should be held constant, and the binary trauma history variable was included as a significant covariate.

Of the 687 women who reported FGM/C, more than 10% of the sample did not report the type, age at procedure, whether or not they had a choice, or whether they knew in advance it was going to happen. When asked whether they recalled physical problems at the time, of the 681 responses, 108 (15.9%) responded that they did not know. These missing data were not associated with meeting criteria for clinically significant distress.

Regarding the recollection of physical problems at the time of FGM/C, 37 women declined to answer. Declining to answer this question was positively associated with meeting criteria for clinically significant distress. Only women who answered the question (yes or no)

were included in analyses of that item (n= 536). All statistical analyses were performed in STATA 14.

5.4 Results

The average age of participants was 31 years old and nearly three quarters (73.7%) identified as Ethnic Somali (Table 2). The majority (69.5%) were born in Somalia, with 19% born in Kenya, and a small proportion (5.2%) born in the US or another Western country. Most participants (70.6%) arrived in the US prior to age 30.

Female Genital Cutting/Mutilation

Seventy-five percent of participants reported having some form of FGM/C, most commonly (30%) Type III infibulation. The second most common was Type I (28%), followed by Type II excision (17%). FGM/C type varied by age, ethnic subgroup, and by immigration status.

FGM/C and Distress

Approximately 15% of participants (n=118) screened positive on the RHS-13 for clinically significant symptoms of distress (Michlig et al., 2019). Among women who did not report FGM/C, 27.7% screened positive for clinically significant distress, while only 12% of the sample with FGM/C screened positive. In bivariate analyses, FGM/C status was significantly protective for clinically significant symptoms (OR=0.36; 95%CI:0.24-0.54) (Table 3). Compared to women who did not report FGM/C, this inverse association was evident for both Type I FGM/C (OR=0.23; 95%CI:0.12-0.42) and Type III FGM/C (OR=0.20; 95%CI:0.11-0.37), but not for Type II FGM/C.

The average age of FGM/C was approximately seven years old. Age of FGM/C (OR=0.9; 95%CI 0.80-1.02), having a choice as to whether or not to undergo FGM/C (OR=0.76; 95%CI 0.31-1.83), or being forewarned of the event (OR=0.81; 95%CI 0.38-1.70) were not associated with meeting the RHS-13 cut-off score. However, women who perceived that healthcare providers in the US discriminated against women with FGM/C were four times as likely (OR=4.03; 95%CI 2.59-6.28) to meet the RHS-13 cut-off score compared with those who did not perceive discrimination.

Among women with FGM/C, of the six types of adverse experiences the most common were extreme pain (18.1%) and pain or difficulty with urination (15.7%). While most women with FGM/C (73.7%) did not report recalling adverse events, of those who did report them, many (81.4%) reported more than one, with a small proportion (15%) reporting experiencing all six. Each adverse experience was significantly associated with reporting clinically significant distress, as did increases in the number of adverse events experienced.

The experience of multiple FGM/C events, often carried out if a girl's first circumcision was considered flawed or if stiches broke open prior to healing, was also strongly associated with reporting clinically significant distress (OR=5.86; 95%CI:2.50-13.76). Collapsing all events into a single binary variable of recalling any of the previously explored adverse events around FGM/C was strongly associated with distress (OR=4.98; 95%CI:2.69-9.19). Of women who reported recalling adverse events at the time of FGM/C, the majority (63.6%) had undergone Type III FGM/C, with fewer (22%) among those with Type II, and the least (14.4%) for Type I.

Compared to women who held the view that all forms of FGM/C should be stopped, those who believed that an adult woman should be able to decide for herself were nearly five times (OR=4.96; 95%CI 2.48-9.91) as likely to meet the RHS-13 cutoff score for

clinically significant distress. Women indicating multiple views were also more likely to meet the cutoff (OR=1.74; 95%CI 1.06-2.84).

Nearly one in four study participants (22.1%) had experienced a non-FGM/C related potentially traumatic experience in her past. These potentially traumatic experiences were highly predictive of current clinically significant distress (OR=19.26; 95%CI 12.00-30.90).

Multivariable Analyses

After controlling for problems at the time of FGM/C, being circumcised lost its significant protective relation with the distress outcome (OR=0.22; 95%CI:0.02-2.98). Similarly, each type of FGM/C lost its independent association with the distress outcome when controlling for the recollection of problems. FGM/C status and type were therefore not retained in the final model.

The final model identified four primary factors associated with clinically significant distress (Table 4). Most significantly, women with histories of trauma were nearly 9 times (OR=8.94; 95%CI:3.81-20.98) more likely and those who recalled adverse FGM/C experiences were almost five times (OR=4.29; 95%CI:1.68-10.97) more likely to meet the cut-off for clinically significant distress. Women who perceived healthcare providers discriminated against women with FGM/C were nearly three times (OR=2.90; 95%CI:1.20-7.02) more likely to report clinically significant distress. Finally, compared to women who believed that all forms of FGM/C should stop, women who thought that adult women should be able to do what she wanted so long as she gave her consent were three and a half times (OR=3.50; 95%CI:0.85-2.53) more likely to report clinically significant distress.

5.5 Discussion

In a refugee sample with a high proportion of women reporting FGM/C, our results suggest that FGM/C was not a homogenous experience and women who recalled pain and suffering at the time of FGM/C were more likely to report currently having clinically significant symptoms of distress. In particular, women who reported Type III FGM/C were most likely to recall adverse outcomes at the time of FGM/C. Among women with FGM/C, distress was also significantly associated with potentially traumatic experiences, and perceived discrimination by healthcare providers because of FGM/C. Though not significant in multivariable analysis, associations between women's attitudes about FGM/C and distress were present. Specifically, the belief that women should have the right to choose FGM/C if they are adults and provide consent was weakly related to distress.

Epidemiological studies to date have often measured FGM/C as a binary variable (circumcised or not), with little attention to the degree of cutting, culturally and psychologically relevant context, and experiential detail pertinent to mental health outcomes. Furthermore, studies of distress among women with FGM/C in Western countries are extremely limited.(AL-KRENAWI & WIESEL-LEV, 1999; Applebaum et al., 2008; Behrendt & Moritz, 2005b; Berg et al., 2010b; Chibber et al., 2011; Elnashar & Abdelhady, 2007; Kizilhan, 2011; Nnodum, 2002; Osinowo & Taiwo, 2003; Vloeberghs et al., 2012)

Although only marginally significant our findings suggest the possibility that, at a group level, circumcision may be protective against current reporting of clinically significant distress; in the U.S. context, FGM/C status may signify strong group membership, providing protective psycho-social benefits related to increased instrumental and emotional support and coping resources such as self-esteem(Bisschop, Kriegsman, Beekman, & Deeg, 2004; Haslam, O'brien, Jetten, Vormedal, & Penna, 2005). A study in Ethiopia found that distress

was less pronounced among women with positive attitudes surrounding FGM/C, suggesting the importance of social recognition and supportive environments in which positive coping may take place(Pechmann et al., 2016). This begs the question of what manner of supportive or unsupportive social ecologies exist for FGM/C-affected women in the US, and how those influence FGM/C's impact on mental health. Further research is warranted on the role of attitude and context in defining the relationship between FGM/C and mental health status.

Our study indicates that holding the belief that adult women should be able to choose whether to undergo FGM/C may potentially be associated with increased risk for distress. While the practice of FGM/C is cultural, and the Qur'an does not call for the practice, the term "Sunna" (meaning: Islamic practice) to describe Type I FGM/C (Table 1) is telling, in that it highlights a religious discourse underlying the practice(Shell-Duncan & Hernlund, 2000). It is possible that prohibition from practicing culturally important rites, especially those related to religious beliefs, may be perceived as discrimination, or group rejection(Verkuyten & Yildiz, 2007). This may be pertinent to FGM/C if a woman believes that the legal or cultural prohibitions in place prevent her from choosing to participate in this as a religious or culturally important rite. A study of Muslim women in New Zealand found that both psychological (pride and belongingness) as well as behavioral (engaging in religious practices) identity formation played important roles in mental health(Jasperse, Ward, & Jose, 2012). Specifically, strong group affiliation amplified the negative effect of religious discrimination on mental health, and engaging in Islamic practices had a protective effect(Jasperse et al., 2012). Our findings also indicate that perceived discrimination by healthcare providers, based on FGM/C status, is related to distress. This corresponds to findings regarding the important role of discrimination in current mental health found among Somali adolescent men and women in the US(Ellis et al., 2010).

Women with FGM/C appear to be differentially affected by other stressors related to the circumcision experience. We found that women who reported recalling problems at the time of the FGM/C procedure were more likely to be distressed. A study of women of various national origins in the Netherlands found that Type III FGM/C and remembering the event were associated with PTSD, anxiety and depression(Vloeberghs et al., 2012). This aligns with our findings that adverse experiences were most frequent in Type III FGM/C (versus in Type I or II), and were associated with distress. Our study also supports emerging evidence that FGM/C experiences vary widely, and that trauma may relate to specific experiences rather than FGM/C status specifically(Agboli, Richard, Schmitz, & Aujoulat, 2019). The Dutch study, one of the only undertaken in the West, found specifically that Somali ethnicity was protective against PTSD symptomology, and that Somalis were less likely to report anxiety and depression compared to other FGM/C practicing groups(Knipscheer et al., 2015).

Study limitations include the lack of a random sample. However, migrant populations remain difficult to enumerate, and this study represents one of the largest data sets on FGM/C among Somalis in the US. Though FGM/C and type of FGM/C occurred prior to the outcome and are unlikely to be incorrectly recalled, distressed women may disproportionately recall other traumatic or negative events that occurred in the past. We were also limited to a single perceived discrimination item. Therefore, these findings may be considered suggestive upon confirmation from future studies with a more robust discrimination scale (such a scale has been added to longitudinal follow-up of this study). The use of trauma and distress as binary variables limits the nuance that we can derive from the results, specifically dose response effects of trauma and severity of distress.

Conclusion

We found that FGM/C for some women with particular experiences such as severe pain and bleeding or multiple cutting events may be a traumatic experience, underscoring the complexities of the relationship between FGM/C and mental health outcomes. Treatment of FGM/C not as a singular experience, but as a set of experiences related to both context and memory of the event will be vital in moving epidemiological research forward and providing appropriate clinical care.

5.6 Tables for Chapter 5

Table 8. Female Genital Mutilation/Cutting Classifications

WHO Type	WHO Classification	Other Common Terms
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 opening with the creation of a covering seal by cutting and sewing closed the labia minora and/or the labia majora, with or without excision of the clitoris	Infibulation Type III/Infibulation is often referred to as "Pharaonic" in practicing communities

(World Health Organization, 2016)

Table 9. Sample characteristics of participating Somali women (N=879), Chapter 5

Characteristic	%	N	M	SD	Range
Age (years)			31.15	13.8	15-90
15-17	12.8	110			
18-25	30.6	263			
26-45	41.1	353			
46-60	11.1	95			
61+	4.5	39			
Ethnicity					
Ethnic Somali	73.7	631			
Somali Bantu	26.3	225			
Marital Status					
Single	42.3	366			
Married	41.9	362			
Divorced/Separated	8.2	71			
Widowed	7.5	65			
Country of birth					
Somalia	69.5	585			
Kenya	19.0	160			
Other Africa/Middle East	6.3	53			
US/Europe	5.2	44			
Immigrant Arrival					
Refugee/Asylee	78.3	611			
Other*	16.0	125			
US Born	5.6	44			
Age of arrival in the US (years)			24.86	17.33	1-88
0-12	21.5	179			
13-17	14.6	121			
18-29	34.5	287			
30-45	19.3	160			
46+	10.1	84			
Annual Household Income					
< 10,000 USD	41.4	247			
10 – 24,999 USD	38.8	231			
>25,000 USD	19.8	106			
FGM/C Status					
No FGM/C	22.6	199			
Yes FGM/C	77.4	680			
FGM/C Type					
Type I	36.9	223			
Type II	23.0	139			
Type III	40.2	243			
Age of FGM/C	7.09	2.27	0-15		

*Includes immigration for the purposes of family reunification, economic or educational development, or other purposes

Table 10. Bivariate associations between Female Genital Mutilation/Cutting factors and distress

	No distress N (%)	Distress N (%)	Odds Ratio (95% CI)
FGM/C status			
No FGM/C	123 (19.13)	47 (39.83)	
Yes FGM/C	520 (80.87)	71 (60.17)	**0.36 (0.24,0.54*)**
FGM/C status by type			
No FGM/C			Ref
Type I (Sunna)	183 (38.45)	16 (28.07)	**0.23 (0.12,0.42*)**
Type II (Excision)	93 (19.54)	26 (45.61)	0.73 (0.42,1.27)
Type III (Pharonic Infibulation)	200 (42.02)	15 (26.32)	**0.20 (0.11,0.37*)**
Contextual factors			
Age of FGM/C procedure	Mean=7.09	Mean=6.56	0.90 (0.80,1.02)
Did you have a choice?			
No	461 (89.17)	65 (91.55)	0.76 (0.31,1.83)
Yes	56 (10.83)	6 (8.45)	
Did you know in advance that you were about to undergo FGM/C?			
No	384 (83.84)	58 (86.57)	0.81 (0.38,1.70)
Yes	74 (16.16)	9 (13.43)	
Are women with FGM/C discriminated against by health providers?			
No	548 (87.4)	74 (63.3)	**4.03 (2.59,6.28*)**
Yes	79 (12.6)	43 (36.8)	
Adverse FGM/C experiences			
Recall physical problem at time of FGM/C?			
No			
Yes	124 (26.38)	29 (59.18)	**4.98 (2.69,9.19*)**
Extreme pain	105 (17.7)	28 (39.44)	**3.75 (2.20,6.39*)**
Excessive bleeding	52 (8.8)	20 (28.17)	**5.98 (3.19,11.21*)**
Shock	47 (7.95)	18 (25.35)	**5.75 (2.99,11.05*)**
Infection	30 (5.08)	12 (16.9)	**5.67 (2.6,12.36*)**
Pain/Difficulty urinating	90 (15.23)	25 (35.21)	**3.8 (2.19,6.61*)**
Long/Difficult recovery	34 (5.75)	15 (21.13)	**7.06 (3.40,14.67*)**
Times experiencing FGM/C			
1	571 (95.97)	62 (86.11)	**5.86 (2.50,13.76*)**
2+	24 (4.03)	10 (13.89)	
Individual attitude towards FGM/C			
All forms should be stopped	409 (77.5)	55 (64.0)	Ref
Pharaonic form should be stopped, but the Sunnah form is ok	78 (14.8)	14 (16.3)	1.33 (0.71,2.52)
All forms should be allowed if the woman is an adult and decides for herself	24 (4.6)	16 (18.6)	**4.96 (2.48,9.91*)**
All forms should continue as they have before	17 (3.2)	1 (1.2)	0.44 (0.06,3.35**)
Number of attitudes expressed			
One view only	528 (85.2)	86 (76.8)	**1.74 (1.06,2.84*)**
Held two or more views simultaneously	92 (14.8)	26 (23.2)	
Presence of potentially traumatic experiences not related to FGM/C			

Trauma History			
No	558 (86.8)	30 (25.4)	**19.26 (12.00,30.90*)**
Yes	85 (13.2)	88 (74.6)	

* p<0.05, **p<0.10

Table 11. Multivariate regression models of Female Genital Mutilation/Cutting and other participant characteristics in relation to distress among Somali migrants

Model 1. – Among all women (N=879)	**OR (95%CI)**
Age (years)	1.00 (0.98-1.02)
Ethnicity	
Ethnic Somali	Ref
Somali Bantu	**3.38 (1.69-6.76)***
Trauma History	**17.42 (9.24-32.82)***
Perception that health care providers discriminated against women with FGM/C	**2.62 (1.34-5.14)***
Attitude regarding FGM/C	
All forms should stop	Ref
Sunna only	0.77 (0.34-1.74)
Belief that adult women should be permitted with consent	2.17 (0.81-5.83)
Traditional practices should continue	0.19 (0.02-1.69)
FGM/C Status	
No FGM/C	Ref
FGM/C	0.50 (0.24-1.05)**
Model 2. Among women with FGM/C (N=680)	**OR (95%CI)**
Age (years)	0.98 (0.95-1.01)
Ethnicity	
Ethnic Somali	Ref
Somali Bantu	1.13 (1.68-10.97)
Trauma History	**8.94 (3.81-20.98)***
Perception that health care providers discriminated against women with FGM/C	**2.90 (1.20-7.02)***
Attitude regarding FGM/C	
All forms should stop	Ref
Sunna only	1.84 (0.67-5.02)
Belief that adult women should be permitted with consent	3.50 (0.85-14.43)**
Traditional practices should continue	1.93 (0.17-22.49)
Adverse FGM/C experiences	**4.29 (1.68-10.97)***

* p<0.05, **p<0.10

Chapter 6. "Whatever You Hide, Also Hides You": A Discourse Analysis on Mental Health and Service Use in an American Community of Somalis

6.1 Abstract

Background

After decades of refugee displacement, Somalis are at increased risk for poor mental health. However, the uptake of treatment referrals in primary care is low among Somalis compared to other refugee groups. The objective of this analysis was to understand the specific resistances to US mental health care contributing to this gap in coverage.

Methods

One hundred and sixty-eight Somalis, including men and women over the age of 14, participated in 28 focus group discussions surrounding Somali wellbeing and healthcare in the US. Transcripts were analyzed based on critical discourse theory, informed by the theoretical work of Michel Foucault.

Results

This study identified two primary discourses, one biomedical and the other driven by Somali community mental health knowledge and social practice. Mental health as an object of Muslim faith, nosological fusion of psychiatric illness terms, and stigmatization and internal social control to limit disclosure were discussed. US mental health services were described as giving off a bad vibe, and represented external institutions of power, exacerbated by perceived discrimination. Somali youth occupied social bridging positions between cultural

vs. US knowledge and practice. Three negotiating discourses emerged wherein participants created discursive solutions to maintain Somali identity while accepting US mental care.

Conclusion

Findings suggest that intervention strategies not only ensure that services are culturally appropriate and sensitive to religion, but also consider that services are potentially seen as both an extension of US institutional power and an affront to Somali identity making. Overcoming these challenges may involve nurturing the negotiating discourses taken up by communities.

6.2 Introduction

Decades of internal conflict and natural disaster in Somalia has resulted in millions of Somalis displaced worldwide. Between 2010 and 2016 more than 47,000 Somali refugees were resettled in the United States, with secondary arrivals increasing that population (e.g. for family reunification)(Refugee Processing Center, 2016). As with other refugee populations, Somalis are at increased risk for common mental disorders among refugees such as anxiety, post-traumatic stress disorder (PTSD) and depression. Factors related to this increased risk include pre-migratory trauma, difficulties along the migratory pathway, and post-migratory factors related to discrimination or acculturative stress (Betancourt et al., 2015; Ellis et al., 2008a; Ellis et al., 2008b; Kirmayer et al., 2011).

Though refugees' risk for mental disorder is high, treatment needs are unmet in the US (McCrone et al., 2005). While primary care clinics often screen for mental disorders, the uptake of treatment referrals in primary care is low among Somalis compared to other refugee groups (Johnson-Agbakwu, Crista E. et al., 2014). This may be partially attributable to differences in US biomedical and Somali mental health explanatory models (Kleinman,

2008). While Somalis acknowledge that social isolation, stressors such as unemployment, and history of trauma may cause poor mental health, additional explanatory models include spirit possession by djinn, the will of God and treatment methods such as exorcism and prayer (Bettmann et al., 2015; Johnsdotter et al., 2011; Markova & Sandal, 2016; Pamela A. Clarkson Freeman MSW et al., 2013; Scuglik et al., 2007; Wedel, 2011; Wolf et al., 2016).

The Behavioral Model for Health Service Utilization, particularly among immigrant groups, suggests that the misalignment of these explanatory models may limit disclosure of poor mental health status or care seeking (Andersen, 1995; Yang & Hwang, 2016). Through the lens of critical race theory, this model has been expanded to encourage exploration of how factors external to the individual, imposed upon them due to their race or other socially marginalizing characteristics, along with perceived discrimination, may impact service utilization (Ford & Airhihenbuwa, 2010b). Finally, recent studies in stigma have found that fears around losing a preferred social identity, or facing social judgement negatively impact service use (Clement et al., 2015). Taken together, this suggests a complex social context that Somalis suffering with mental disorders must navigate in the US (Figure 7).

By what method might we begin to understand the making of mental health in a US Somali community, and how do these complex factors encourage or constrain the behavior of Somalis regarding mental health service use? Through critical discourse analysis (with attention to competing discourses across generations and cultural spaces), we aimed to explore how statements about mental health created or reinforced particular knowledge about mental health, and subsequently offered specific identities.

6.3 Methods

Data Collection & Procedures

These data were collected for a study to improve healthcare for women affected by female genital cutting in the state of Arizona. Ethical approval was received by Arizona State University (STUDY00005252). Qualitative data were collected between October 2017 and November 2018 through eight three-hour community forums (Table 1). The first two hours of each forum included health education and discussions in a forum setting; in the third hour, smaller focus groups were organized by age (youth/middle-aged/elder).

Community forums were held separately for men and women, Ethnic Somali and Somali Bantu, and for the Phoenix and Tucson metropolitan areas. Four Somali facilitators, matched to the gender of the forums taking place, recruited participants under the supervision of a Somali research team member. Facilitators attended a two-day training covering research ethics, study design, and qualitative data collection techniques. Facilitators were bilingual in English and either Somali or Maay Maay. Each forum began with obtaining informed oral consent. A mixture of English, Somali, and Maay Maay were spoken throughout, with translation provided between the languages by facilitators where necessary. Focus groups were conducted according to a semi-structured guide (Appendix III).

Forums and focus groups were audio recorded, then transcribed and translated to English. One focus group audio, among middle aged Somali Ethnic women, was lost due to recorder malfunction. Another focus group, among Somali Bantu male youth, was removed from analysis due to thin data quality.

Participants

We recruited 168 Somali participants, over age 14 residing in the Phoenix or Tucson metropolitan areas (Table 1). Maximum variation sampling was employed to increase the likelihood that data would contain both demographic and phenomenal variation, meaning

that the data might represent a broad spectrum of experiences and opinions in the Somali community (Sandelowski, 1995).

Data Analysis

Analysis was undertaken by the first author, who holds a master's degree in Anthropology and has doctoral level training in qualitative analysis and medical anthropology. It began with repeated reading of the audio transcripts to familiarize herself with the text. Memoing and *in vivo* coding was first used to highlight salient quotes in the transcripts, which were then organized into themes (Table 2) (Saldaña, 2012). These themes did not constitute the framework for the subsequent analysis, but permitted a thematic landscape as a starting point from which the analysis could begin. Transcripts were then reread to evoke specific insights into the discourses present in the text, informed by the work of Michel Foucault (Parker, 2014; Willig & Smith, 2003).

According to Foucault, the analysis of texts, in this case focus group transcripts, begins by occupying a critical stance against psychology as a "body of knowledge" to be applied (Arribas-Ayllon & Walkerdine, 2008). To do this, we investigated how different knowledges are produced about what mental health is, how differences in ways of knowing control behavior as it relates to mental health care seeking, and how they create subjectivities (socially created identities) which Somalis can occupy regarding mental health (Arribas-Ayllon & Walkerdine, 2008). Foucault saw knowledge not as a stable possession, but as an activity, created and contextual, which served as a process through which power positioned individuals into knowable subjects. Given that knowledge determined what could (and could not) be known about an individual, it defined rules and boundaries regarding behaviors,

including how individuals occupied their identities and came to know themselves (Foucault, 1982).

Through the reading the transcripts we asked the following questions, gradually building an outline of discourses and their impact on mental health and care seeking (Jackson & Mazzei, 2011). How are discursive objects such as "mental health" or "care" created? How are these discourses limiting or creating subjects (possible identities)? What activities ensue as a result, what behaviors do they create? Is there resistance to particular subject positions being offered by each discourse?

Reflexivity

Rigor in qualitative analysis, particularly as it pertains to critical analyses, suggests that analysts be highly aware of their social and cultural position vis á vis the study population (Berger, 2015). As first author and primary analyst I maintained an awareness of my positionality as a white, US-born woman. While I have worked with the Somali community in several capacities over the last eight years, I sought to increase the quality of this analysis through self-reflection, triangulation between qualitative and quantitative results in the overall study, and debriefing meetings with facilitators immediately following focus groups. The first author undertook reflexive memoing during the analysis, and results were discussed with Somali and other team members.

6.4 Results

Two primary fields of discourse emerged from the analysis, one aligned with the US biomedical model of mental health, and a second aligned with traditional Somali cultural and religious knowledge (Figure 8). Each was associated with particular therapeutic behaviors. On its surface, the biomedical discourse was an obvious counter discourse to traditional

knowledge; however, a third field emerged in which participants attempted to negotiate between these often opposed ways of knowing about and coping with mental health concerns.

"Partial Hate"

Foucault argued that systems of thought are brought about by the historical operations of power; that each discourse has a genealogy since "the world of speech and desires has known invasions, struggles, plundering, disguises, [and] ploys" (Foucault, 1978).

Discourse in the US around immigration often forebodes a mass third world invasion, inspired by ongoing preoccupation with texts such as The Camp of the Saints, a novel first published in France in 1973 which narrated the fall of western civilization to incoming migrants (Blumenthal & Rieger, 2017). At the time of this data collection (2017-2018) the US presidential administration enacted the Travel Ban, restricting the ability of Somalis to immigrate given their "security threat" (Trump, 2017a; Trump, 2017b). Language evoking systems of thought traceable back to the events of September 11, 2001 and beyond, where Muslim and Arab identities in the US were constructed with the imagery of the enemy (Merskin, 2004).

Participants described personal and community struggles to overcome their intersectional marginalization at the axis of their identities as immigrants, Muslims, and Africans in the U.S. One elderly Ethnic Somali man noted "We are even below minorities. Somalis are the least to be considered." An elderly Somali Bantu man reported that he "*live[d] like a second class citizen"* and many reported feeling under attack, or singled out. Participants described fears of deportation, and coming to terms with not being reunited

with loved ones still overseas. One middle-aged Ethnic Somali woman shared, *"You feel uneasy… you fear you are not accepted by the [American] society."*

While experiences of outright discrimination by healthcare professionals were rare, there were instances where participants reported being treated dismissively by physicians, or looked at strangely by administrative staff. A middle-aged Somali Bantu woman described having healthcare staff assume she was illiterate, recalling her internal thoughts at the time, *"You don't have to talk slow to me."* These factors may play a role both in mental health and service use, since it is within this context that Somalis navigated their mental health and care seeking. However, this sense of "partial hate" was not necessarily a discourse of its own, but rather a trace element that existed in the material of other discourse.

Islam & Mental Health

Mental health as an object of experience and discourse was often defined as connectedness to God and the community. Causation for poor mental health was cited as due to withdrawal from God, or not being social enough. This intersection of faith, community, and mental wellbeing resulted in masjids being spoken of not only as places for prayer, but also where physical space was held for community unification and belonging, directly impacting mental health and the ability to self-care, since treatment for mental disorder was a return to God. "*If someone is god-fearing, their faith will see them through difficulties,"* explained one Elderly Ethnic Somali Man. Participants accentuated the importance of being patient, steadfast, and persevering in the face of adversity.

"Things that cannot be said out loud": From Community-Level Discourse to Cultural Identity

Knowledge was produced in the Somali community not only by identifying mental health as an object of faith, accessible and treatable through religious texts and the cultivation of individual faith, but also as a component of community identity. Meaning that in a Somali community, where families and social networks are tightly intertwined and interdependent, an individual's mental health was often seen as a direct reflection of, or threat to, the community or family as a whole.

At the community level, mental disorder was often described using an umbrella term such as "craziness" or "madness", and did not draw clear distinctions between Western psychiatric categories (i.e. generalized anxiety vs. major depression) nor often recognize spectrums of severity in mental disorder, conflating common distress with serious mental illness. Consequentially, individual's displaying any signs of mental illness may be called mad, or viewed as potentially risky to the community.

Somalis sought to constrain the behavior of those with poor mental health in several ways. For instance, gossip was used to alert the community to aberrant behavior in individuals, which was linked in discourse to protecting other people from any danger that individual may cause. A young Ethnic Somali man described how, hypothetically, if a child who was "mentally disabled" had "done some bad stuff" a Somali parent would feel obligated to disclose that information for instance to a medical provider, to *"give him notice of what he did or what he is going to do to you, to let them know to just be aware of what is going to happen, so there is no risk involved then."*

Participants also described that nicknames would sometimes be created, and that bullying took place. A middle-aged Ethnic Somali man shared that people would "notice that this person is seeking [mental] help and then say, 'hey, this person is crazy.' They are just going to start calling him ['Crazy']." Further explaining:

> *If someone has stress and shares it with you, we think they have schizophrenia, depression, anxiety. All of these have their respective medication… but Somalis would only pronounce you possessed by demons if you have the symptoms of any of the above illnesses. They think your condition can't be reversed...*

Consequently, disclosure within the community could make matters worse. Many reported fearing that disclosure would lead to their children would be taken away by US social services or others. Closer to home, women reported that it may be considered grounds for divorce.

This particular production of mental health knowledge and its subsequent social consequences promotes a Somali identity resting heavily on psychological resilience and the self-management of mental health. Participants expressed this by noting that Somalis were emotionally quite strong, that they did not agonize about the problems that befell them, nor did they wish to burden others with their problems. A middle-aged Ethnic Somali woman shared her concern that people were *"pressured by the community in a way that forces them not to talk [about their mental health]."*

Despite the focus on resilience, there was talk that mental struggles were in fact common. A middle-aged Ethnic Somali woman believed that many *"deny the existence of [a mental health] problem, while in reality everyone might experience it at one time or another."* A middle-aged Somali Bantu man similarly stating, *"Everyone has some sort of craziness."* An elderly Ethnic Somali man agreed, once again concluding that some may hide mental illness to avoid the social consequences of disclosure:

> *Like with the elderly people, there are things that cannot be said out loud, like depression. [if you tell someone you're depressed] the person will ask you; "Are you mad?... if yes, you should be brought to the mental hospital." It happens in this country that a person looks good and is doing his daily job, and yet his mind is not present.*

Resisting Biomedical Knowledge/Power

This subject position of an emotionally resilient Somali was sometimes positioned in contrast to the biomedically offered subject position of *"mental patient"*. Psychiatric productions of knowledge and related healthcare was problematized against this backdrop of Somali identity making. One participant referring to psychiatrists as *"the pill doctor"*. In a focus group of young Somali Bantu women the following exchange took place between five participants

> *P1: I feel like being overwhelmed can lead to anxiety.*
> *P2: … and depression and all the other disorders that Americans have.*
> *P3: Woah, you don't think Somalis have those problems too?*
> *P3: It's not just Americans.*
> *P2: I don't mean to segregate things right here. But… Americans are wimps, that's what I think…*
> *P4: Yeah, they have a word for everything!*
> *P5: Seriously.*
> *P2: They're like, "ohhh you're having a 'this' attack." [laughter] I'm like, I don't know, I'm just frustrated maybe.*

This resistance to the subject position (externally enforced identity) of "patient" and the production of knowledge offered by psychiatry was furthermore influenced by distrust in western medicine overall. Participants described fear of physician error, pharmaceutical side effects, high healthcare costs, and poor or improper care. One elderly Ethnic Somali man shared that medical interventions could be seen as an unwelcome outside force that individuals might purposefully hide from:

> *Some of us were brought up in villages. There used to be outreach health assistants who undertook immunization programs. We ran away from them. It might be the same here. We used to come back [to the village] when they were gone.*

Finally, beyond general distrust was also a frank disgust. Participants shared concerns that US medicine used *"dead bones"* and *"dead organs"*. Participants reported that mental health providers would ask about things not culturally acceptable to discuss; making talk therapy "talking taboo." In sum, US healthcare gave a *"bad vibe."* In contrast, the more familiar cultural prescriptions of prayer and sociability was considered wholesome. One young

Somali Bantu woman described the impact to treatment adherence behaviors among older Somalis:

> *They [older generations] just think that American medicine… they just think there's something wrong with it. Like they're trying to drug you or something. So if the doctor gives them a pill they will not take that pill at all…. the orange pill bottle, with the white top… will stay in the cabinet for days… YEARS. When you're moving out, you see it, it says 2004 and it's still full. [laughter]*

Youth in Discourse: Multiple Resistances, Multiple Subjectivities

Discourses surrounding mental health and treatment within the Somali community were not universal. Notably, differences existed between the older and younger generations. While older generations generally referred to all mental illness as *"madness,"* youth often utilized psychiatric illness terms. Youth appeared largely familiar with general disorder classifications, and often took up expert positions during discussions, citing US university-level education on the topic.

Some youth shared confusion regarding how to navigate this social position; bridging Somali cultural understandings of mental health and western psychiatric notions. In a focus group of young Ethnic Somali men, one young man asked, "*How the heck do I tell my father that I have depression in Somali?"* While this was partly a discussion regarding the translation of the word, he also expressed concerns regarding the conversation as a whole. Youths shared their perceived importance of what they termed *"deep talk",* or *"actual talk",* which they saw as absent between Somali parents and children. Another young Ethnic Somali man explained:

> *It's like we live in a community where we don't talk about it, we don't get deep about stuff. You can't really… there's no one to go to if you're feeling sad or something. On [American] TV shows, or whatever, if the daughter is having a bad day or something, they talk about it as a family, but in our kind of culture it's not really like that.*

Meanwhile, in a focus group of middle-aged Ethnic Somali women, a mother shared:

It has caused me continuous anxiety, thinking of children and their mothers, fathers and their children, men and their wives who are separated. Massive separation has taken place and now you can see many single mothers' level of stress is increased dramatically due to the [Travel] Ban. Their husbands are still in Africa, and they have to play both the roles of father and mother. You can see why some people are saying that Somali teenagers are lost. The reason is because their mothers don't have enough time with their children, they don't know what is happening.

Negotiating Discourses

These discourses suggest that Somalis in the US navigate their mental health amidst the backdrop of both marginalization and shifting knowledges. Discursive tension existed largely in three domains, 1) how Somali identities could be renegotiated to include US mental health service use and deep talk while maintaining their capacity for resilience, 2) opposition between viewing mental health as an object of faith compared to the biomedical model, and 3) resistance to western medicine from older generations while youths actively explored western expert positions. Some participants were not only cognizant of these competing discourses, but eagerly took up diplomacy between them. What emerged were new discourses, negotiating knowledges and redefining social rules in the hopes of resolving tensions between power and offer new subject positions to mentally ill individuals.

Negotiating Discourse 1: Whatever you hide also hides you

One such discourse sought to allow psychological care while maintaining Somali emotional resilience. An elderly Somali Bantu man disclosed his own struggles with mental health*:*

I once suffered from depression [participant notes that at the time he was facing deportation and a marital separation]… Life got very difficult for me, hope fading. If I went to another Somali, I know they would have stigmatized me. I went for counseling where the doctor lent me an ear and gave me advice. I wasn't given any medication, rather he listened to me and gave me advice. I should have received the same from my community.

A conversation ensued regarding how most individuals hide their mental struggles, with one participant noting, *"It all lies on the community to identify mentally ill people who require attention. There are a few brave people like [the man who disclosed] who can compose themselves and get to a doctor."* One man finally concluding, *"There is a Somali proverb that goes, 'Whatever you hide also hides you.' You should get to them [US mental health providers] and seek their help."*

In this new discourse, individuals who disclosed mental health concerns were not spoken of as wimps, burdens, or risks, but instead as brave and composed. This agreed with Somali self-sufficiency and resilience. Regarding communal responsibilities, an Elderly Somali Bantu man warned, *"If a person harms himself as a result of you bullying or stigmatizing him, you will be responsible for his woes,"* creating within this discourse a new social accountability counteracting bullying and stigmatization traditionally used to discourage disclosure.

Negotiating Discourse 2: Trust in God, but tie your camel

Perhaps the most pronounced discursive tension existed between biomedical and local mental health knowledge when it came to specifically seeking US metal health services. This was a tension particularly felt by youths given their bridging social positions. In one focus group of young Somali Bantu women the following exchange took place:

> *P1: Yeah, it's helping each other [to pray for/with a sick person], but at the same time, if it's a medical situation, if the first thing you're thinking in your head is "oh let me go get the Quran"… I don't think I'm not going to say it's bad, because it's not, but at the same time, that's not necessarily healthy for someone. If there's aspects to where… like if a girl was on her period, and she's cramping, you can read the Quran… I don't know if you guys have done this.*
> *P2: My dad did that for me.*
> *P1: Yeah, that's helping, but at the same time if someone breaks their leg and just sitting here reading [the Quran] like it's just going to tie back together…*
> *[Participant described instance where someone had broken their leg]*
> *P3: Did they take him to the hospital?!*
> *P1: He sat there and he wrapped it and read the Quran on it like it was going to come back together.*
> *P3: Nooooo!*

> *P4: [loudly, explaining] it's that the recitation would cause him less pain, it's not that it's going to fix up his leg or anything, it's going to cause him less pain. But the thing is you have to have done that, and then go to the hospital.*

Participants who engaged in this negotiating discourse repositioned mental health care seeking as a sign of resourcefulness and practicality. It furthermore challenged the notion that such individuals were leaving behind Somali values, being unfaithful to Islamic beliefs, or being ruled by the western biomedical discourse. In a focus group of elderly Ethnic Somali men, one participant specifically paraphrased, *"you should trust your God, and tie your camel."* Similarly highlighting the importance of doing one's due diligence when it came to health.

Negotiating Discourse 3: We came here, and we will be here

Far from finding education and social bridging among youths to be a threat, older generations encouraged the education of youth, particularly in the health fields. Older generations believed that youth would then be in a position to create spaces of cultural safety for Somali patients and work within US educational and health institutions to promote understanding and respect for Somali perspectives and values. An elderly Ethnic Somali man described the impact through the following analogy:

> *For example, when I visited Minnesota, I went to a bank and there was a man who deals with the Somali people who don't [speak English]. One of the reasons why people move out of this state [Arizona] is we don't have that kind of service… We came here, and we will be here, so we need our own people to be trained as doctors.*

This discourse not only negotiated away particular concerns related to discrimination and outsider status in the US context, but also offered the potential to counteract the "bad vibes" around western medicine. Furthermore, training Somali medical experts repositioned Somali youth not as immigrants, or security threats, but instead as contributing to US systems. Not "Americanized", but actively integrating Somali knowledge into the US

healthcare system and reciprocally integrating US psychiatric knowledge and care into the Somali community.

6.5 Discussion

This study identified two primary discourses among the study population regarding mental health and service use, including a discourse about the biomedical approach to mental health in the US, and a discourse of Somali mental health and social practice. Participants described mental health as an object of their Muslim faith, and how within the community diagnostic categories or severity of mental illness were not recognized, leading to stigmatization and forms of internal social control to limit disclosure. Mental health services available in the US, drawing on biomedical knowledge, were described as giving off a bad vibe, and represented external institutions and power from which individuals might need to hide. These discourses took place on the backdrop of perceived discrimination against Somalis in the US. Somali youth in particular faced challenges confronting their mental health needs as they occupied social bridging positions between cultural knowledge and practice and US knowledge and practice. Three negotiating discourses emerged wherein participants created discursive solutions to maintain Somali identity while accepting US mental care.

Participants' descriptions of the interconnectedness of their faith as Muslims and mental health traces to the production of knowledge about the self in Islam. Muslims are tasked with the sacred duty of embodying both purity and faith (*fitrah*), the manifestation of which includes psychological resilience and strong interpersonal connectedness. Therefore, mental health struggles might be viewed as an indication of straying from this path, or a trial sent by God to test one's faith (Rashed, 2015). Our findings agree with current efforts to

tailor mental health interventions to Muslim populations. This includes a recent piloted intervention of Islamic trauma therapy which incorporated cognitive and exposure therapy into faith discussions (Zoellner et al., 2018).

At the community level, the nosological fusion of psychiatric illness terms under the umbrella of "madness" has two potential implications. Nosological fusion refers to instances where one emic (non-biomedical) term is used to encapsulate a variety of etic (biomedical) illness terms (Young, 1979). In the case of malaria, nosological fusion was found to leave parents unable to distinguish between less serious childhood febrile illnesses and more serious cases of malaria, negatively impacting their ability to seek appropriate care and resulting in poor health outcomes (Makemba et al., 1996). It may be that in the case of mental health among Somali populations in the US, similar nosological fusion may not equip households and communities to respond to individuals in moments of psychological crisis. Furthermore, the inability to discern between mental illnesses and illness severity may partially explain stigma against even more mild common problems among the mentally ill (Bettmann et al., 2015; Wedel, 2011; Wolf et al., 2016).

These findings lend further insight into why Western treatment for mental illness is often considered a last resort for this population, expanding on prior studies documenting fear of pharmaceutical side effects, discomfort with talk therapy, and low health literacy (Bettmann et al., 2015; Johnsdotter et al., 2011; Scuglik et al., 2007; Wedel, 2011; Wolf et al., 2016). This analysis supports that treatments currently used within the community commonly include reading the Quran, healthy diet and exercise, and mobilizing families to provide support, as found in prior research . This is relevant given that preferences towards alternative, traditional treatments may play a role in limiting immigrant health service utilization (Yang & Hwang, 2016). What the critical analysis of these discourses adds is the

notion that care seeking for mental health among Somalis in the US is more complex than mere notions of cultural safety, but operates in an arguably inhospitable discursive environment.

The contextual significance of the current sociopolitical climate in these discourses expands on past research finding that Somali patients have encountered discrimination by mental health workers (Wedel, 2011). Through the perspective of intersectional theory, which proposes that people who are marginalized on several fronts can experience these marginalizations in amplified ways (Kimberle Crenshaw, 1991), a recent study of women in the US found that as intersectional discrimination experiences accumulated, the risk of depression rose (Bcares & Zhang, 2017). However, the impact of the subjectification of Somalis both on their described mental health status and on their interactions with US medical systems goes beyond the minutia of interactions in the clinical space. In Foucault's critique of institutions, he explored how certain subject positions, such as "criminal", or "mentally ill" are inextricably linked to the mechanics of power being exercised through social institutions such as courts and hospitals. Indeed Foucault argued that criminality and mental illness historically have been linked, as a tactic of social control (Foucault, 2008; Foucoult, 1975). While it is unclear if Somalis are explicitly making this connection, it is no wonder that in a time where Somalis have been subjectified as "security threats" that they are hesitant to engage with US mental health systems. Yet, justified efforts to increase the mental wellbeing of Somali migrant communities in the US can neither be reduced to a discussion of culture, nor can it be reduced to the raised fists of politics.

Central to this discussion, and to the emergence of the three negotiating discourses identified in this study, is the notion of identity making. Symbolic interactionism as a theory posits that we interact with the world around us based on the meanings ascribed to particular

things, and that through our interactions we ascribe meaning (Blumer, 1986). A required premise of symbolic interactionism is that we must first announce our own identity in relationship to the world, in order to become involved in it as a social actor (Snow, 2013). In other words, as Somalis in the US make up their minds regarding the meaning of mental wellness and make decisions regarding how and where to seek care, this is inextricably tied to how they announce, or renegotiate, their identities. This may be particularly salient for young Somalis occupying social bridging positions, which while undoubtedly mazelike, may offer bridging social capital shown to have a positive effect on self-rated health (Kim, Subramanian, & Kawachi, 2006).

The results of this analysis are interpretive and are limited by the discussions which took place during the focus groups, which were not limited to topics around mental health but also included broader inquiry around female genital mutilation/cutting. Future research would benefit from a more narrow focus on mental health. Stigma within the community may have caused many not to share their opinions regarding these matters. The analysis is furthermore dependent on the quality of the translation provided for those focus groups not held in English. However, this study captured a wide range of Somali voices, across genders, generations, and ethnic subgroup, and the use of focus group data allowed rich conversations to emerge for analysis. It is likely that there are similarities between these discourses and those in other Somali populations in resettlement, or among other resettled groups.

The findings of this critical analysis suggests that public health solutions to increasing mental health service utilization among Somali migrant communities in the US take a multi-pronged approach. Intervention strategies should likely not only ensure that services are culturally appropriate and sensitive to religion, but should also consider that services are

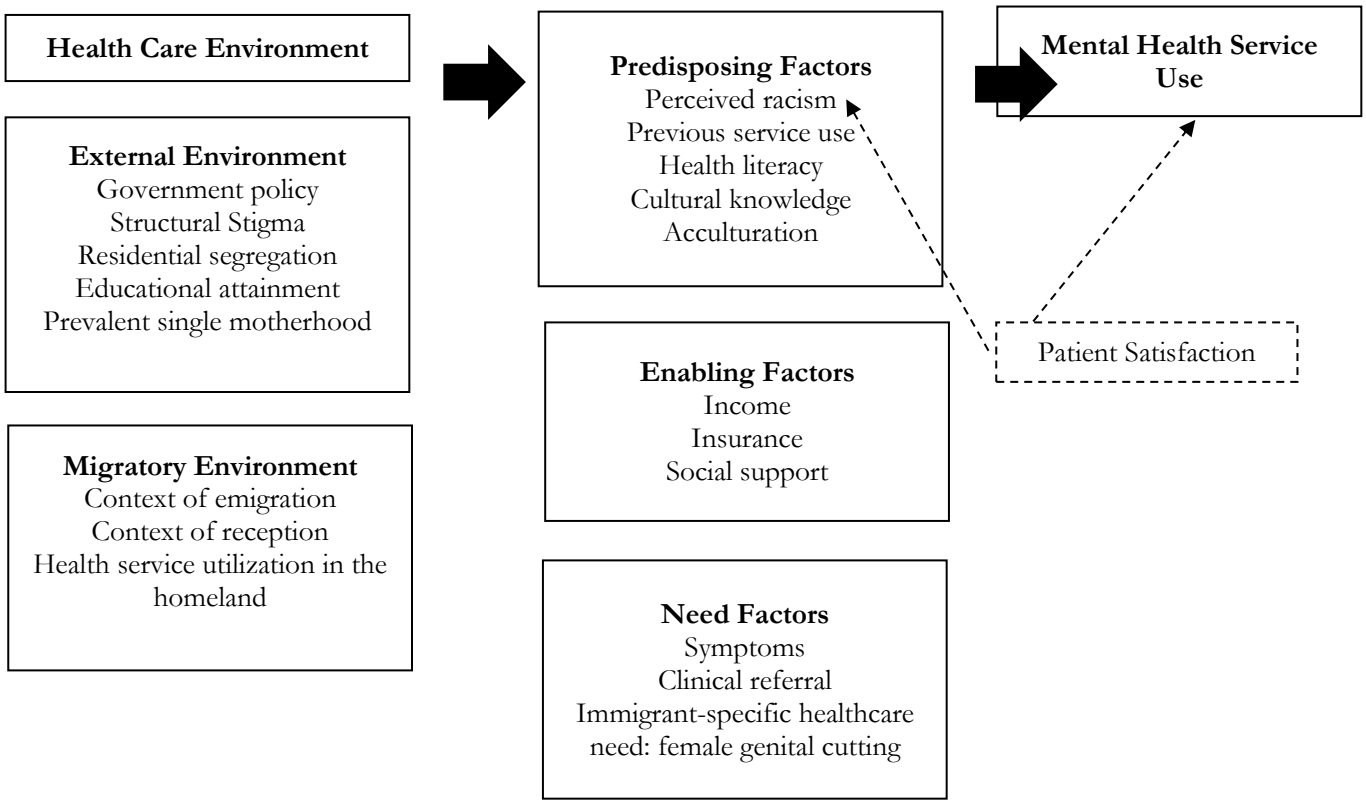
potentially seen as both an extension of US institutional power and an affront to Somali identity making. Overcoming these challenges may involve nurturing the negotiating discourses being taken up within the communities.

6.6 *Tables for Chapter 6*

Table 12. Community Forum & Focus Group Participation (N=168)

Phoenix (n= 84)												Tucson (n=84)											
Ethnic Somali (n=42)						Somali Bantu (n=42)						Ethnic Somali (n=42)						Somali Bantu (n=42)					
Forum: Male (n=21)			Forum: Female (n=21)			Forum: Male (n=21)			Forum: Female (n=21)			Forum: Male (n=21)			Forum: Female (n=21)			Forum: Male (n=21)			Forum: Female (n=21)		
Youth Focus Group (n=7)	Middle-aged Focus Group (n=7)	Elder Focus Group (n=7)	Youth Focus Group (n=7)	Middle-aged Focus Group (n=7)	Elder Focus Group (n=7)	Youth Focus Group (n=7)	Middle-aged Focus Group (n=7)	Elder Focus Group (n=7)	Youth Focus Group (n=7)	Middle-aged Focus Group (n=7)	Elder Focus Group (n=7)	Youth Focus Group (n=7)	Middle-aged Focus Group (n=7)	Elder Focus Group (n=7)	Youth Focus Group (n=7)	Middle-aged Focus Group (n=7)	Elder Focus Group (n=7)	Youth Focus Group (n=7)	Middle-aged Focus Group (n=7)	Elder Focus Group (n=7)	Youth Focus Group (n=7)	Middle-aged Focus Group (n=7)	Elder Focus Group (n=7)

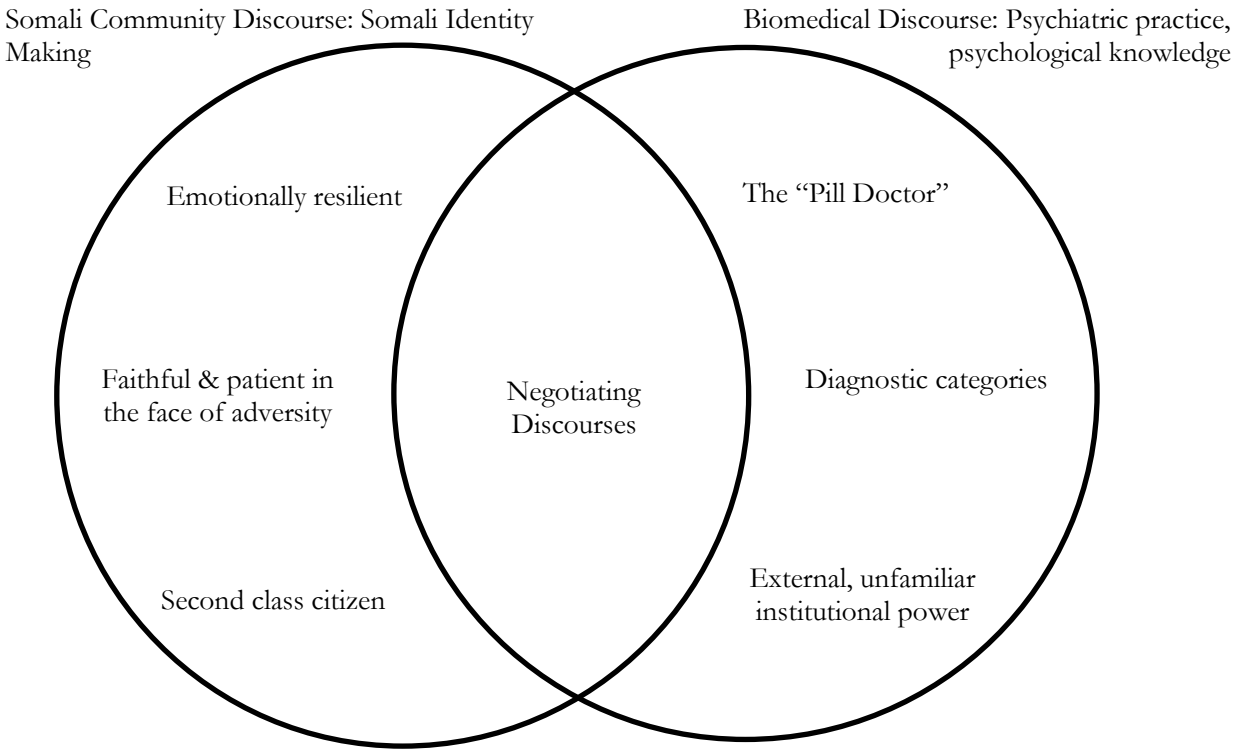
Figure 7. Adapted Behavioral Model of Mental Health Service Use among Somali in US



Stigma-related Factors
Dissonance between preferred self/social identity and mental illness stereotypes
Need/preference for non-disclosure
Anticipated experience of social judgement

*(Andersen, 1995; Clement et al., 2015; Ford & Airhihenbuwa, 2010b; Yang & Hwang, 2016)

Figure 8. Discourses on mental health



Chapter 7. Conclusions

7.1 Summary of results

Research Question 1.1 & 1.2 Does the RHS-13 and the recommended cutoff value of ≥11 **appear valid in Somali women?**

Factor analysis loaded all scale items onto a single factor explaining 75.6% of the variance. This agrees with past factor analyses conducted (Hollifield et al., 2016), and suggests that the psychometric properties of the screen are operating in this study population of Somali migrant women as expected. Using trauma history as a criterion variable to discriminate for distress, a cutoff value of 11 returned a sensitivity of 50.9% and a specificity of 94.9%. Smaller cutoff of 9 or 10 offer small gains in sensitivity with little change in specificity. This indicates that institutions using the cut off score of ≥11 can be confident in the screen's ability to correctly identify Somali women who are not experiencing clinically significant distress; however, in order to increase the ability of the screen to properly identify women with distress, women with scores of 9 and higher could potentially be referred to care.

Research Question 1.3 Do positive screens associate in the anticipated directions with histories of trauma, poor physical health, and perceived discrimination?

External construct validity found positive screens to be associated with histories of trauma (OR=19.25;95%CI 12.00-30.90), perceived post-migration discrimination (OR=4.27;95%CI 2.73-6.67), and self-rated health (OR=2.05;95%CI 1.68-2.49) in the expected directions.

Research Question 1.4 What percent of the study population screens positive for clinically significant distress?

Among Somali migrant women in the state of Arizona, approximately 15% of the study population screened positive for clinically significant distress, and the majority (55%) with mild distress. Those screening positive most frequently reported thinking too much, and least frequently reported reliving a traumatic experience.

Research Question 2.1 What are the non-FGM/C-related predictors of positive screens?

Among all women, multivariable analysis found that predictors of clinically significant distress included being Somali Bantu as opposed to Ethnic Somali (OR=3.38;95%CI 1.69-6.76), having had one or more potentially traumatic experiences (OR=17.42;95%CI 9.24-32.82), and post-migration perceived discrimination in the healthcare setting (OR=2.62;95%CI 1.34-5.14).

Research Question 2.2 Controlled for age, ethnicity, and other predictors, do any FGM/C-related variables associate with current distress?

In a refugee sample with a high proportion of women reporting FGM/C (77.4%), our results suggest that FGM/C was not a homogenous experience. Among all women (with FGM/C and without) multivariable analysis found no significant association between FM/C and clinically significant distress (OR=0.50;95%CI 0.24-1.05). However, among women with FGM/C those who recalled pain and suffering at the time of the procedure were more likely to report current distress (OR=4.29;95%CI 1.68-10.97). In particular, women who reported Type III FGM/C were most likely (63.6%) to recall adverse outcomes at the time of FGM/C. Though not significant in multivariable analysis, associations between women's attitudes about FGM/C and distress were suggestive. Specifically, the belief that women should have the right to choose FGM/C if they are adults and provide consent was related to distress (OR=3.50;95%CI 0.85-14.43), though not reaching statistical significance.

Research Question 3.1 What discourses exist in the community that inform, or impact service usage?

This study identified two primary discourses among the study population regarding mental health and service use, including a discourse about the biomedical approach to mental health in the US, and a discourse of Somali mental health and social practice. Participants described mental health as an object of their Muslim faith, and how within the community the nosological fusion of psychiatric diagnostic categories and severity under a single umbrella term of madness lead to stigmatization and forms of internal social control to limit disclosure.

Research Question 3.2 What subject positions (identities) are available to Somali women when deciding whether or not to disclose mental health status or seek mental health services?

The identity of "mental health patient" offered by the biomedical model was seen as "wimpy" by some participants, wherein Americans were perceived as overemphasizing mental challenges and overly relying on medical services to address their woes. In contrast, subject positions hinging on the core values of Somali identity encouraged resilience and fortitude in the face of poor mental health. Somali youth in particular faced challenges confronting their mental health needs as they occupied social bridging positions between cultural knowledge and practice and US knowledge and practice.

Research Question 3.3 What sites of resistance exist which may explain Somali women's non-use of US mental health services?

Mental health services available in the US, drawing on biomedical knowledge, were described as giving off a bad vibe, and represented external institutions and power which individuals might seek to evade. These discourses took place on the backdrop of perceived

discrimination against Somalis in the US. Furthermore, the biomedical subject position of patient misaligned with Somali identity making, which focused on resilience in the face of mental challenges. In order to overcome these resistances to mental health care seeking, three negotiating discourses emerged wherein participants created discursive solutions to maintain Somali identity while accepting US mental care. These included repositioning help seeking and service use as brave and responsible actions on the part of the individual, reliance on medical models of mental health care not as counter to Islamic knowledge but practical additions to treatment, and the value of educating Somali youth to enter the US healthcare system as specialists in order to incorporate Somali knowledge and values and create safe cultural spaces for treatment.

7.2 Overall conclusions

These findings suggest that clinically significant distress is present in this community, and that the lack of uptake of mental health referrals is likely due to sociocultural and macrostructural concerns, rather than the invalidity of mental health screening. Mental health screens in primary care should likely be coupled with focused conversations regarding the implications of mental health care seeking with Somali patients. Physicians and other providers might find it profitable to use the language generated in the negotiating discourses of the community to encourage patients with positive screens to follow up on the referrals provided.

As it pertains to FGM/C and mental health, providers should remain cognizant of the fact that the experience of FGM/C may or may not be traumatic to individual women, and that trauma associated with the experience, if present, may relate to traumatic memories of the experience, or strongly held opinions on the practice. Most importantly, providers

should note that Somali women, regardless of their FGM/C status, have myriad risk factors for poor mental health, including non-FGM/C related trauma histories and ongoing discrimination in the US. The qualitative evidence in particular suggests strongly that the current sociopolitical climate in the US has caused resounding impacts on Somali's mental health. Somali Bantu, as opposed to Ethnic Somalis, appear particularly at risk.

7.3 Strengths and limitations

Related to the validity study a primary limitation is the lack of a clinical interview for use in criterion validity. Throughout the quantitative analyses, the measurement of discrimination using a single item decreases confidence in those results; a comprehensive instrument on discrimination would strengthen confidence in the associations suggested, however the qualitative findings support the quantitative findings. While the study sample was not random, migrant populations remain difficult to enumerate, and this study represents one of the largest data sets on FGM/C among Somalis in the US, and which we believe is representative of the Somali community. The cross-sectional nature of the analysis is also a limitation. Though FGM/C and type of FGM/C occurred prior to the outcome and are unlikely to be incorrectly recalled, distressed women may disproportionately recall other traumatic or negative events that occurred in the past. The use of trauma and distress as binary variables limits the nuance that we can derive from the results, specifically dose response effects of trauma and severity of distress. The results of the qualitative analysis are interpretive and are limited by the discussions which took place during the focus groups, which were not limited to topics around mental health but also included broader inquiry around FGM/C. Stigma within the community may have caused many not to share their

opinions regarding these matters. The analysis is furthermore dependent on the quality of the translation provided for those focus groups not held in English.

Despite these limitations, the use of community-based participatory research methods permitted data collection during a time of duress in the US Somali community. Longitudinal follow up with participants from this study, collected in 2019, offers the potential for additional insights into distress within this population. This also represents the largest quantitative sample of Somali women's health collected in the US to date. The qualitative data set, furthermore, captured a wide range of Somali voices, across genders, generations, and ethnic subgroup, and the use of focus group data allowed rich conversations to emerge for analysis. It is likely that there are similarities between these discourses and those in other Somali populations in resettlement, or among other resettled groups. The findings of this study are potentially transferrable to other Somali, refugee, or FGM/C-affected groups. While a lack of exclusive focus on mental health during the focus groups might be viewed as a limitation by some, the orientation of mental health topics within the broader context of questioning regarding FGM/C and service use is also a strength.

7.4 Recommendations for future research

Future research might benefit from looking more in depth into specific diagnostic categories, such as anxiety disorder or PTSD, given that these diagnoses may have different risk factors than distress. In regard to FGM/C and mental health, while this research hopes to have achieved its aim to move the needle forward on our understanding of this relationship, much additional research is required. Most significantly, increasingly rigorous epidemiological designs are required, both internationally and domestically, to more clearly support causal inferences between FGM/C and mental health. This might include

longitudinal studies as ethics permit. The findings of this study strongly suggest that the evidence must move beyond looking at FGM/C as a binary variable, instead exploring aspects of the initial and ongoing experience of FGM/C as our results show. This might include further study of the importance of women's opinions regarding their own FGM/C status on current mental health, or the potential protective effects related to group membership that FGM/C might offer. As it pertains to therapeutic intervention for this population, while the WHO currently recommends cognitive behavioral therapy for FGM/C-affected women, this recommendation is unsupported by any current evidence(World Health Organization, 2016). Given that this study suggests that FGM/C is not experienced as traumatic for all women, further research into how cognitive behavioral, or other exposure therapy, might specifically approach FGM/C-affected women would be beneficial. The discourse analysis' finding that Somali identity making in regards to mental health heavily rests on emotional resilience and prayer suggests that mental health promotion and prevention efforts may be particularly well received by this community, and suggest further research in that domain.

Chapter 8. Policy recommendations

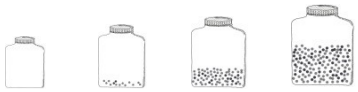
The findings of this study suggest a strong link between US policy and Somali women's mental health. The current Travel Ban that halted Somali refugee arrivals had important implications in the qualitative data analysis related to family reunification among Somali refugees This specifically related to the difficulties faced by single mothers disconnected from their support networks, children and adolescents not benefiting from the additional support of complete families, and ongoing worries about loved ones still overseas.

Beyond targeting of the Somali population for refugee-related policy, FGM/C itself has in recent years become hotly debated in the US after the arrest of a Michigan physician found performing FGM/C in her practice and the subsequent overturning of the federal law banning FGM/C(Fortin, 2017). As a result, FGM/C law is currently enacted at the state level. As Somalis attempt to navigate their mental health in this environment of increased surveillance over their bodies, particular attention should be paid to ensuring that Somali communities are not ostracized. Local healthcare systems, particularly those servicing Somali populations, should ensure that healthcare providers are appropriately trained on FGM/C and how to approach discussions of mental health in a patient-provider encounter. Enhanced mental health referral strategies for Somali patients is warranted.

Chapter 9. Appendices

9.1 Refugee Health Screener 13 (RHS-13)

Instructions: Using the scale beside each symptom, please indicate the degree to which the symptom has been bothersome to you over the past month. Place a mark in the appropriate column. If the symptom has not been bothersome to you during the past month, circle "NOT AT ALL."



SYMPTOMS	NOT AT ALL	A LITTLE BIT	MODER-ATELY	QUITE A BIT	EXTREM ELY
46. Muscle, bone, joint pains	0	1	2	3	4
47. Feeling down, sad, or blue most of the time	0	1	2	3	4
48. Too much thinking or too many thoughts	0	1	2	3	4
49. Feeling helpless	0	1	2	3	4
50. Suddenly scared for no reason	0	1	2	3	4
51. Faintness, dizziness, or weakness	0	1	2	3	4
52. Nervousness or shakiness inside	0	1	2	3	4
53. Feeling restless, can't sit still	0	1	2	3	4
54. Crying easily	0	1	2	3	4

The following symptoms may be related to traumatic experiences during war and migration. How much

in the past month have you:

55. Had the experience of reliving the trauma; acting or feeling as if it were happening again?	0	1	2	3	4
56. Been having PHYSICAL reactions (for example, break out in a sweat, heart beats fast) when reminded of the trauma?	0	1	2	3	4
57. Felt emotionally numb (for example, feel sad but can't cry, unable to have loving feelings)?	0	1	2	3	4
58. Been jumpier, more easily startled (for example, when someone walks up behind you)?	0	1	2	3	4

9.2 Modified Bicultural Involvement Questionnaire (M-BIQ)

<Use hand-held laminated Visual Analog Scale of Smiley Faces for the Likert questions in this module>

1. How often do you speak your native language?

a) At home ☐ Never ☐ Sometimes ☐ Always
b) At work ☐ Never ☐ Sometimes ☐ Always
c) With friends ☐ Never ☐ Sometimes ☐ Always
d) In general ☐ Never ☐ Sometimes ☐ Always

2. How often do you speak English?

a) At home ☐ Never ☐ Sometimes ☐ Always
b) At work ☐ Never ☐ Sometimes ☐ Always
c) With friends ☐ Never ☐ Sometimes ☐ Always

d) In general ☐ Never ☐ Sometimes ☐ Always

3. How often do you enjoy: ☐ Never ☐ Sometimes ☐ Always

a) Music from your native country ☐ N ☐ S ☐ A
b) Dances from your native country ☐ N ☐ S ☐ A
c) Restaurants with a flavor of your native country ☐ N ☐ S ☐ A
d) TV programs/movies from your native country ☐ N ☐ S ☐ A
e) Radio stations from your native country ☐ N ☐ S ☐ A
f) Books and magazines from your native country ☐ N ☐ S ☐ A
g) Shopping in ethnic stores representing your culture ☐ N ☐ S ☐ A
h) Going to traditional/religious ceremonies/events ☐ N ☐ S ☐ A

4. How often do you wear traditional/ethnic attire from your native country?

a) To work ☐ Never ☐ Sometimes ☐ Always
b) At home ☐ Never ☐ Sometimes ☐ Always
c) To special occasion/ceremonies/events ☐ Never ☐ Sometimes ☐ Always

5. If I had my own choice, I would live:

☐ In the same neighborhood as people from my own culture
☐ Away from people of my own culture
☐ I have no preference where I live

6. How often do you enjoy:

☐ Never ☐ Sometimes ☐ Always

a) American music
b) American dances
c) American restaurants/food

d) American tv programs/movies
e) American radio stations
f) American books and magazines
g) Shopping in American stores
h) Going to American ceremonies/events

7. Sometimes life is not as we really want it. If you could have your way, how would you like the following aspects of your life to be like? Please select the column that applies to you.

I wish this would be:

	Completely from my culture	Somewhat from my culture	Completely American
A. Food			
B. Music			
C. Attire			
D. Dance			
E. Neighborhood			
F. Shops			
G. Friends			
H. Radio/TV programs			
I. Language			

9.3 Focus Group Discussion Questions

Sometimes Somalis, even when there is treatment available for mental wellbeing, don't use those services. For instance, among the women who reported sadness or nightmares less than half said that they every sought professional help.

What problems do women in your community have with their thoughts and feelings?

What do you think causes women to have these problems?

If female circumcision is related to these problems, how is it related?

Why are Somali women NOT seeking mental health services from professionals in the US?

Who would Somali women feel most comfortable talking with about emotional issues (another Somali woman, or a non-Somali)? Why?

How can the US healthcare system improve mental health services to be more appropriate for Somali people?

Here in the US, three of the most common problems with mental wellbeing are depression (feeling sad and not wanting to be around anyone), anxiety (thinking too much and worrying really bad) and PTSD (having bad memories that won't go away, maybe having nightmares or being angry). From the results of the survey we can see that at least 1 woman in 20 has pain in their thoughts, feelings and emotions.

How would you be able to recognize a person that was having problems with their thoughts, feelings or behaviors in the Somali community? What would you notice?

Who would be the appropriate person to approach a woman who is suffering mentally about her problem?

What might be the barriers to approaching someone in your culture? How could you overcome those barriers?

Some women reported feeling discriminated against, looked down on, or afraid to seek health services. During the men's forums, many men also believed that Somalis were looked down on.

Have you personally always been treated with respect by health providers or other service organizations here in the US?

Can you describe times when you or others have felt disrespected?

What fears do people have around seeking healthcare in the US?

Chapter 10. References

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Young, A. (1979). The dimensions of medical rationality: A problematic for the psychosocial study of medicine. *Toward a new definition of health* (pp. 67-85) Springer.

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Zoellner, L., Graham, B., Marks, E., Feeny, N., Bentley, J., Franklin, A., & Lang, D. (2018). Islamic trauma healing: Initial feasibility and pilot data. *Societies, 8*(3), 47.

Chapter 11. Curriculum Vitae

I have worked in the domain of refugee women's health for over 8 years, beginning with programmatic activities at the Refugee Women's Health Clinic in Phoenix, Arizona. During my masters studies I served as chairwoman of that clinic's community advisory coalition research subcommittee, and have subsequently been involved in several research projects regarding refugee women's sexual, reproductive, and mental health. Understanding not only the mechanisms of health and health behavior, but also how public health interventions can ensure the enrollment and retention of hard to reach populations is a unifying subject of my research. Beyond this work my interests also lie in humanitarian settings broadly, with work exploring the experiences of healthcare workers in Mosul, Iraq during ISIS occupation, and international response to the Ebola epidemic in West Africa. Over the past decade the attention of researchers has also been drawn to the effects of climate change in humanitarian crisis, and my work includes studies both on the effects of drought on the health of pastoralists in Northern Kenya, and new work proposed to address wildfires here in the US.

EDUCATION

2019	Ph.D. International Health, Social & Behavioral Interventions Johns Hopkins School of Public Health
2018	Certificate, Public Mental Health Research Johns Hopkins School of Public Health
2015	M.A. Global Health Arizona State University, School of Human Evolution and Social Change
2012	B.A. Anthropology Arizona State University
2007	Certificate, Russian Language Fluency Far Eastern National University, Vladivostok, Russia

OTHER TRAINING & EXPERIENCE

2019	Coding and Analyzing Qualitative Data- Johnny Saldaña Johns Hopkins School of Public Health: Baltimore, MD
2018	Humanitarian and Disaster Response Simulation Training Project Hope: Virginia, USA

2017 Advanced Study Institute in Transcultural Psychiatry
McGill University: Montreal, Quebec

2013-2015 Chairwoman, Research Subcommittee
Refugee Women's Health Advisory Coalition
Refugee Women's Health Clinic: Arizona, USA

AWARDS & FELLOWSHIPS

2018-2019 Ruth L. Kirschstein National Research Service Award
National Institutes of Health

2016-2018 T32 Fellowship in Global Mental Health
National Institute of Mental Health

2015-2017 Tuition Scholarship, Department of International Health
Johns Hopkins Bloomberg School of Public Health

PUBLICATIONS

2019 **Michlig, G. J.,** Lafta, R., Al-Nuaimi, M., & Burnham, G. (2019). Providing healthcare under ISIS: A qualitative analysis of healthcare worker experiences in Mosul, Iraq between June 2014 and June 2017. *Global public health*, 1-14.

2019 Mahmood, A. A., Shah, D. D., **Michlig, G. J.,** Hughes, M. E., & Bass, J. K. (2019). Assessing Predictors of Emotional Distress by Immigrant Type: An Exploration of Adult Refugees, Asylees, and SIV Holders in Maryland. *Journal of immigrant and minority health*, 1-11.

2018 **Michlig, G. J.,** Westergaard, R. P., Lam, Y., Ahmadi, A., Kirk, G. D., Genz, A., ... & Surkan, P. J. (2018). Avoidance, meaning and grief: psychosocial factors influencing engagement in HIV care. *AIDS care*, 30(4), 511-517.

2018 Greenberg, A., **Michlig, G. J.,** Larson, E., Varallyay, I., Chang, K., Enobun, B., ... & Harvey, S. A. (2019). "I knew I could make a difference": Motivations and barriers to engagement in fighting the West African Ebola outbreak among US-based health professionals. *Qualitative health research*, 29(4), 522-532.

2017 Gaughan, M., & **Michlig, G. J.** (2017). Reproductive Health Policy Variability Among the States Over Time: Implications of the Affordable Care Act of 2010 for Health Researchers. In *Applied Demography and Public Health in the 21st Century* (pp. 37-50). Springer, Cham.

2017 Zachary, W. W., **Michlig, G**., Kaplan, A., Nguyen, N. T., Quinn, C. C., & Surkan, P. J. (2017, June). Participatory Design of a Social Networking App to Support Type II Diabetes Self-Management in Low-Income Minority

Communities. In *Proceedings of the International Symposium on Human Factors and Ergonomics in Health Care* (Vol. 6, No. 1, pp. 37-43). Sage India: New Delhi, India: SAGE Publications.

Under Review **Georgia J. Michlig**, Cynthia Mackey, Crista Johnson-Agbakwu. Acculturation, Measurement & Health in a Population of Somali Refugee Women in the U.S.

Under Review **Georgia J. Michlig**, Nicole Warren, Merry Berhe, Crista Johnson-Agbakwu. Female Genital Cutting in the U.S. State of Arizona: Evidence of Treatment Access, Health Service Use & Care Experiences.

Under Review **Georgia J. Michlig**, Merry Berhe, Crista Johnson-Agbakwu. Health Care Seeking Behaviors among a Population of Somali-American Women in the United States.

Under Review Elizabeth L. Fox, Adan Kabelo, **Georgia J. Michlig,** Fatuma Abdi, Abigail Reich, Irene Tombo, Haley Swartz, Jessica Fanzo. *"Survival of the fittest"*: Pastoralists' livelihoods and capabilities in northern Kenya.

In Prep **Georgia J. Michlig**, Pamela J. Surkan, Judith Bass, Karin Wachter, Crista Johnson-Agbakwu. Female Genital Mutilation/Cutting and Psychological Distress among Somali Women in the United States.

In Prep **Georgia J. Michlig**, Crista Johnson-Agbakwu, Michael Hollifield, Judith Bass, Pamela J. Surkan. Properties of the Refugee Mental Health Screen (RHS-13) and Predictors of Distress among Somali Women in the United States.

INVITED TALKS

2019 Female Genital Mutilation/Cutting and Mental Health: Emerging Theory, Research and Implications for Practice. US Department of Health and Human Services Office on Women's Health, Webinar on Clinical Care for Women Affected by FGM/C.

2018 Inequality & Migration in the Globalized World. Guest Lecturer, Columbia University, New York, NY.

2014 Oral Testimony to Legislature. Civil Society Listening Session on the U.S. Domestic Response to FGM/C. Washington, DC.

CONFERENCE PRESENTATIONS

2019 Being Somali and Healthy in America: A Critical Analysis of Community Discourse on Healthcare in a Somali American Community (Oral). Society for Applied Anthropology Conference, Portland, OR.

2018 Properties of the Refugee Mental Health Screen (RHS-13) and Predictors of Distress among Somali Women in the United States (Oral). North American Refugee Health Conference, Portland, OR.

2018 "A thing that cannot be said aloud" Psychological Distress in a Circumcised Community. 2nd International Expert Meeting on Female Genital Mutilation/Cutting (Oral). Montreal, Canada

2018 Intergenerational Differences in FGC-related Attitudes and Behaviors: A Mixed Methods Exploration in a Population of Vast Acculturative Variation (Poster). 2nd International Expert Meeting on Female Genital Mutilation/Cutting, Montreal, Canada

2017 Mental Health Outcomes and Care-seeking among Somali Women in the US: Negotiating the Cultural and Cross-Cultural (Poster). Society for the Study of Psychiatry and Culture, Princeton, NJ.

2015 A Culturally-Informed Educational Program to Promote Sexual Health and Well-Being among Refugee Women (Oral). North American Refugee Healthcare Conference, Toronto, Canada.

2015 Acculturation and the Impact of Migration on the Sexual Health of Somali Refugee Women (Poster). Population Association of America Conference, San Diego.

2015 Developing a Comprehensive Contextual Model of Reproductive Health Policy: Implications of the Affordable Care Act of 2010 (Poster). Population Association of American Conference, San Diego, CA.

TEACHING EXPERIENCE

Academic Teaching Assistantships

2019 Issues in Mental Health Research in Developing Countries (graduate level) Johns Hopkins School of Public Health.

2019 Ethics of Public Health Practice in Developing Countries (graduate level) Johns Hopkins School of Public Health.

2018-2019 Qualitative Research Practicum (graduate level) Johns Hopkins School of Public Health.

2018 Issues in Mental Health Research in Developing Countries (graduate level) Johns Hopkins School of Public Health.

2016 Health Behavior Change at the Individual, Household and Community Level (graduate level) Johns Hopkins School of Public Health.

2013 Epidemiology (undergraduate level) Arizona State University

2013 Environmental Health (undergraduate level) Arizona State University

Other Teaching/Mentorship Experience

2014-2015 Qualitative Research Mentor. Pathway Scholars Program**,** University of Arizona
School of Medicine.

2005-2007 English as a Second Language. English First, Vladivostok, Russia.

RESEARCH ACTIVITY

2015- Present Enhancing Culturally-Informed Health Care Services for Women affected by Female Genital Cutting in Arizona
Field site: Refugee Women's Health Clinic, Arizona USA
Co-advisors: Judy Bass, PhD, Pamela Surkan PhD, ScD
Funding: Department of Health and Human Services, Office on Women's Health

2019- Present Post-Occupation Mental Health in Mosul, Iraq
Research Assistant, Johns Hopkins School of Public Health
Primary Investigator: Gilbert Burnham, MD
Funding: Johns Hopkins International Health Faculty Supported

2019-Present The Impact of Wildfires and Climate Disruption on Mental Health in the Circumpolar North
Research Assistant, Johns Hopkins School of Public Health
Primary Investigator: Jura Augustavincius, PhD

2018- 2019 Integration of Muslim Immigrants into Baltimore City Policy and Health Services
Research Assistant, Johns Hopkins International Injury Research Unit
Primary Investigator: Adnan Hyder, MD, PhD
Funding: 21st Century Cities Initiative, Johns Hopkins University

2017-2018 Adaptation and Coping of Healthcare workers in Mosul, Iraq during ISIS
Research Assistant, Johns Hopkins School of Public Health
Primary Investigator: Gilbert Burnham, MD
Funding: Johns Hopkins International Health Faculty Supported

2015-2017 Understanding and addressing moral dilemmas of sedentarisation of pastoralists: Practical ethics of mitigating conflict amongst water and food resource constrained populations in the Northern Kenya Semi-Arid Lands
Research Assistant, Johns Hopkins School of Advanced International Studies
Primary Investigator: Jessica Fanzo, PhD
Funding: Johns Hopkins Berman Institute of Bioethics, Practical Ethics Grant

2015-2016 A Diabetes Networking Tool (DNT) to Enhance Self-Management through Social Networks (mHealth)
Research Assistant, Johns Hopkins School of Public Health
Primary Investigator: Pamela Surkan, ScD
Funding: NIH, National Institute of Nursing Research R21

2014-2015 Developing a Comprehensive Contextual Model of Reproductive Health Policy: Implications of the Affordable Care Act of 2010
Research Assistant, Arizona State University
Primary Investigator: Monica Gaughan, PhD
Funding: Arizona State University

2013-2015 A Culturally-Informed Educational Program to Promote Sexual Health & Wellbeing among Refugee Women
Research Associate, Maricopa Integrated Health, Refugee Women's Health Clinic
Primary Investigator: Crista Johnson-Agbakwu, MD
Funding: Patty Brisben Foundation

2003-2004 Proteomics of Glioblastoma Multiforme
Laboratory Research Assistant, Barrow Neurological Institute
Primary Investigator: Adrienne Scheck, PhD

ACADEMIC SERVICE

Reviewer Journal: AIDS Care

DEPARTMENTAL/UNIVERSITY SERVICE

2018-2019 Mental Health Graduate Network. Faculty Training for Student Mental Health. Johns Hopkins School of Public Health.

2015-2016 Doctoral Student Committee. Johns Hopkins School of Public Health.

COMMUNITY SERVICE/INVOLVEMENT

2016-2017 Adult GRE Instructor. Clay Pots Non-Profit. Baltimore, MD.

2015-2016 Volunteer Judge. We the People: High School Civic Education Finals. Phoenix, AZ, Baltimore, MD.

2014-2015 Volunteer. Somali American United Council. Phoenix, AZ.

2011-2014 Volunteer. Refugee Women's Health Clinic. Phoenix, AZ.

2013-2014 New Roots Farm & Community Garden Support Volunteer, International Rescue Committee. Phoenix, AZ.

ANALYTIC SOFTWARE SKILLS

Qualitative Analysis: NVivo10, Anthropac
Quantitative Analysis: STATA, MPLUS
Social Network Analysis: R, UCINet