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Refugee and asylum-seeker health seeking in the greater Boston area

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BOSTON UNIVERSITY
SCHOOL OF MEDICINE

Thesis

**REFUGEE AND ASYLUM-SEEKER HEALTH SEEKING
IN THE GREATER BOSTON AREA**

by

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B.S., Georgia Southern University, 2015

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requirements for the degree of
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DEDICATION

I would like to dedicate this work to my family and the clients that I have worked with at the “Place”.

ACKNOWLEDGMENTS

I would like to acknowledge my fellow candidates for the Masters of Science in Medical Anthropology and Cross-Cultural Practice, for helping to push me and encourage me when persevering became difficult. I would also like to thank the faculty for guiding me when I felt lost. A special thanks to the “Place” for acting as the site for a great deal of my research as well as letting me become so involved in the amazing work that you do.

REFUGEE AND ASYLUM-SEEKER HEALTH SEEKING IN THE GREATER

BOSTON AREA

MEGHAN MORILLO

ABSTRACT

In this research project, I examine the role that three organizations play in the greater Boston area. I sought to understand how these organizations were offering care to this population, and, in a broader sense, what it means to care for asylum-seekers and refugees. To answer this question, I developed a qualitative study that consisted of semi-structured interview and participant observation at three different sites from August 2015 through February 2017. I argue that the agencies where I did my research demonstrated that healthcare does not equal medical care. These agencies offered an integrative approach to overall care for those refugees and asylum-seekers utilizing their services. This care reflected the pre-defined needs and desires of refugees and asylum-seekers while also remaining fluid and adapting to individual cases.

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LIST OF ABBREVIATIONS

CDCCenter for Disease Control

TB.....Tuberculosis

UNHCR.....United Nations High Commission for Refugees

UN.....United Nations

INTRODUCTION

I am finally back at the “Place”, my happy place; a step away from the world of school and waitressing. A space where I can feel like I’m making a difference, an amalgamation of rooms with beautiful paintings and stark office furniture, long off-white corridors splattered with signs differentiating the “Place” and Child Psychiatry offices, and the sound of laughter in spite of the horrors being conveyed behind closed doors. (Fieldnotes January 2017). I began my internship at the “Place” in a time when refugees and asylum-seekers were steadily gaining attention in the mainstream media. During the summer of 2015 the Syrian civil war was gaining infamy as the death toll rose among refugees escaping the horrors of their war-torn home towards Europe via the Mediterranean Sea. The “Place”, boasting the first spot on an internet search engine for “refugee health + Boston”, was being bombarded with applications for volunteering and internship opportunities. I was later told that my work in Malindi, Kenya in combination with my enrollment in a graduate program for Medical Anthropology helped to earn me an interview.

While the media’s attention on refugees did help to peak my interest in the population, it was my time spent in Kenya that initially led me to the population. During the summer of 2013 I decided that I wanted to go to Africa. I had heard amazing stories about the diverse cultures and interesting people found around every corner in the expansive continent. I found a group that helped to set me up with a host family and volunteer position at the Malindi District hospital, a medical center located in a small

coastal town. While there, I had many conversations about not only the political climate, but also the refugees who were displaced within Kenya. Strife in the neighboring country of Somalia made, and continues to make, Kenya an epicenter for refugees. Camps such as Dadaab, are infamous within the region and sparked an unbroken conversation about refugees residing within Kenyan borders. Whether negative or positive, the dialogue surrounding refugees seemed to surround me at every corner while in Malindi and led to my interest in refugees and asylum-seekers living inside the United States.

Arriving at the “Place” on a cold January morning, I immediately unlocked the Patient Navigator room and went to grab a Styrofoam cup. I filled the cup with hot water from the waiting room and tossed in a green tea packet while glancing around, sending a quick greeting to my co-workers before heading back to the Navigator room. After glancing at the schedule for the day, I noted that there was a new patient coming in for their first appointment, or as the staff at the “Place” called it, an intake; scheduled for 10:30 that morning. This gave me a little over an hour to start the call log for the following week. At around ten, I glanced into the waiting room and was startled to see a woman sitting under our brightly colored painting sniffing as she glanced up at me. I quickly walked up to her offering tea or water and asking what her name was. “Mary” she responded softly as she looked at me with tear filled eyes.

Mary was “the intake” for the day and had arrived promptly for her appointment. As our intake began I tried to keep the conversation light. We discussed services offered at the “Place” but even this conversation became heavy as she questioned her eligibility of a food pantry referral and her ability to get to both primary care and mental health

appointments due to transportation constraints. The further we got in the intake the more intense our discussion became. Mary noted several times that she never thought that she would ever need mental health care. She told me of the horrors she had witnessed and the people that she felt she had betrayed through her political actions. The Women's March, on January 21st, 2017, had been the weekend before. A global protest that set out to advocate for policies surrounding women's rights as well as human rights, immigration reform, healthcare reform, worker's rights, LGBTQ rights, racial inequality, freedom of religion, and the environment (<https://www.womensmarch.com/>). This protest garnered a great deal of support around the world and as I heard Mary describe how she had tried to advocate for women in her home country, I couldn't help but think of how much she truly embodied what the march had set out to do. The intake continued and I learned of her many accomplishments as a linguist and a social worker.

After speaking to Mary for over an hour, I sat in the Navigator room for almost an hour thinking about our discussion. Such an accomplished woman, a woman who had dedicated her life to helping others, dedicated her life to working against policies and structures that oppressed people, an amazing woman who was subjugated to horrors beyond belief. Who was I to offer help in any form to her? As a graduate student with minimal mental health training I could offer little more than an ear to listen to and a sad smile as she spoke. While I could only offer intangibles in the form of body language, it seemed to be enough for Mary as she referred to me as an "angel" to the social worker who met with her to finish the intake.

Research Question

As I began my interactions with refugees and asylum-seekers at the “Place”, I had many questions. I was interested in infectious diseases and how they interacted with the population. I was curious about the physical healthcare that refugees and asylum-seekers wanted. I had also heard the term health literacy being thrown around. I hoped to find any connection between refugees and asylum-seekers that the term offered. After working at the “Place” and interacting with the population for over six months, I developed a question that aligned with what I had observed and learned. How does a refugee or asylum-seekers’ understandings of health and healthcare affect how they navigate the United States healthcare system? This question would allow me to look at all aspects of health and healthcare that refugees and asylum-seekers encountered while still enabling an exploration into the causation of certain actions.

Research surrounding refugees and asylum-seekers tends to look at the population in connection to mental illness and mental health treatment. There has also been a great deal of research that looks at refugees and asylum-seekers and physical health ailments such as infectious diseases within the population. Health compliance is an emerging field of research that tries to determine ways to increase compliance among the population while determining reasons behind non-compliance. The field of refugee and asylum-seekers’ health has quickly developed and continues to evolve as the number of refugees, asylum-seekers, and internally displaced persons increases exponentially due to conflict and natural disasters. This influx of research has developed both quantitatively and

qualitatively and focuses on discussions ranging from health to gender roles, and even social media. The goal of my study is to find out ways to increase the overall health outcomes of refugees and asylum-seekers as determined by the population as well as the biomedical community. By advising with the community and asking how they deem themselves to be healthy, I hope to add to the conversation on healthcare compliance by offering an alternative route that would allow biomedical providers to discuss how to increase overall health outcomes as defined by both groups.

Refugees and Asylum-Seekers in Boston

In 2015 alone Massachusetts welcomed almost two thousand refugees into the state. Over the past three years, an average of 456 asylum cases have been granted but that does not account for the number of asylum-seekers in the state (Mass.gov).

Throughout the state, refugees and asylum-seekers have settled down in different neighborhoods. In Springfield, for example, a community of over 150,000 people hosts over 1,500 refugees from various countries, over 350 of them from Somalia (VICE Larson, J. 2014).

In recent months, politics surrounding refugees and asylum-seekers have become volatile as immigration laws dealing with specific populations have been introduced by executive order by President Trump. On the first night of the ban, lawyers, activists, and members of Senate arrived at the Boston Logan International Airport to lend aid to immigrants impacted by the executive order.

Research Design

My initial research design varied from month to month. At one point, I hoped to use translators to help initiate interviews with an Iraqi population. I was finally able to narrow down my design after I had come up with my research questions. My study involved a combination of participant observation and interviews with refugees and asylum-seekers over a combination of three separate locations. Throughout the summer of 2016 I continued my work as a Patient Navigator at the “Place” as well as volunteering at Immigration and Refugee Hope. Both groups offered help to the population but in differing capacities. I was able to conduct semi-structured interviews at the “Place” as well as a third site called the Helping Center.

BACKGROUND

Refugee: (1685) A Protestant who fled France to seek refuge elsewhere from religious persecution in the 17th and 18th centuries, esp. following the revocation of the Edict of Nantes in 1685 ("refugee, n." OED Online. Oxford University Press.)

Creation of the term refugee

Being forced to flee from one's home is not a new concept. Historic texts, such as the Bible, tell stories of invading kings and armies, battles won and lost, and subsequently the displacement of those who have been expelled by enemy forces. Moses, a prominent prophet of the Abrahamic religions was best known for leading a group of Hebrew slaves through the desert after they fled Egyptian rule. World War II ripped through Europe leaving families dismantled, homes destroyed, and the human spirit in waste. Images of concentration camps strewn throughout Europe illustrated the true depth of human depravity and illuminated the need for laws regarding persecution.

Three years after the end of the war, in 1948, the United Nations drafted and the "Declaration of Human Rights", a declaration consisting of thirty articles whose aim was to set a baseline for the basic needs and rights of a person (United Nations, *Universal Declaration of Human Rights*, 1948). While the declaration set a standard for how human life should be treated, it did nothing to help rebuild the lives of, or give autonomy to the thousands of displaced Europeans who were forced to flee from their homes in the war.

The 1951 Geneva Convention rectified the experiences of the displaced Europeans three short years later. At the Geneva Convention, the United Nations (UN) worked hard to define what constituted a refugee; the convention also gave rights and benefits to refugees residing in countries that ratified the document. The Convention initially defined refugees as people who were displaced within Europe prior to 1951. This definition limited the inclusivity of the term and was amended in 1967 to encompass those being persecuted on all continents as international conflicts gained recognition

The UN defines a refugee as

“(S)omeone who has been forced to flee his or her country because of persecution, war, or violence. A refugee has a well-founded fear of persecution for reasons of race, religion, nationality, political opinion or membership in a particular social group. Most likely, they cannot return home or are afraid to do so. War and ethnic, tribal and religious violence are leading causes of refugees fleeing their countries.”(UNCHR, *What Is a Refugee*, 2016)

In order to be legally considered a refugee, a person must be able to prove that they are unable to return to their own country due to fear that they may lose their own life or be persecuted upon return.

“U.S. immigration law does not list specific examples of the kinds of persecution that would qualify someone for asylum or refugee status. However, from the law that has been developed through court cases, we know that it can include such acts as threats, violence, torture, inappropriate imprisonment, or denial of basic human rights or freedoms.” (NOLO Bray and J.D. 2016)

The one exception to this rule is that of a war criminal.

“A refugee does *not* include anyone who ordered, incited, assisted, or otherwise participated in the persecution of any person on account of race, religion, nationality, membership in a particular social group, or political opinion” (USCIS, *Learn About the Asylum Application Process*, 2015).

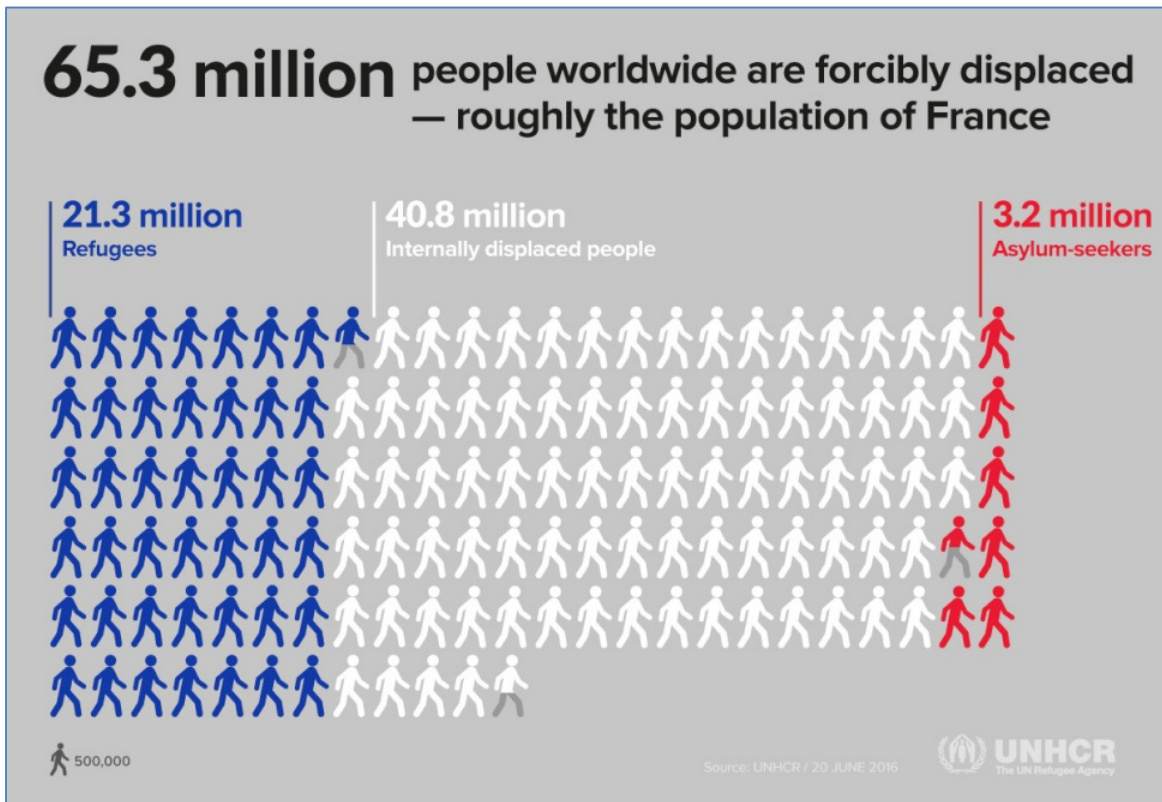


Figure 1: <http://www.unhcr.org/news/late> 1

There are estimated to be more than 65 million displaced people in the world today including over 20 million refugees. This number is almost double the number of refugees in the world only two years ago. Since 1975 the United States has received 3,252,493 refugees from around the world with the greatest numbers coming in from regions in Africa, Asia, and Southeast Asia (Department Of State. *The Office of Website Management*, 2015) This does not take into account those who have been internally displaced within their own country and by either choice or force, have not been able to flee the country yet or who are considered to be stateless.

Who are asylum-seekers?

The number of refugees in the world also fails to account for asylum-seekers.

Asylum-seeker is a term used to denote a person who is forced to flee from their homes due to persecution. The UN has described asylum seekers as follows:

“When people flee their own country and seek sanctuary in another country, they apply for asylum – the right to be recognized as a refugee and receive legal protection and material assistance. An asylum seeker must demonstrate that his or her fear of persecution in his or her home country is well-founded.” (UNCHR: What Is a Refugee, 2016)

In order to file for asylum, the person must be residing within the country in which they wish to be documented. This is a difficult task due to the long journeys that many asylum seekers must make to get to safety and as they do not enter the country with a protected political identity, they are subject to exploitation. People applying for refugee status on the other hand are not allowed to apply for the status within the United States, instead they must patiently wait to hear if they had received the status or not before entering.

The defining factors of both a refugee and asylum-seeker require that they both have left the physical borders of their home country and have a well-founded fear of persecution if they were to return to their home country. While a person may have fled their country, and demonstrated a well-founded fear of persecution or death, it is up to the government in which they are seeking shelter to determine if they will be politically identified as a refugee or asylum-seeker. While the United Nations High Commission of Refugees (UNHCR) may identify a person as a refugee or asylum-seeker as such, it is

ultimately the receiving countries decision to uphold and give the benefits that the political identities require.

Rights of a refugee and asylum-seeker

When a refugee or asylum-seeker has gained their legal status in the country they are speaking asylum in, they are granted rights under the 1951 Geneva Convention. The most basic but most serious is non-refoulement. Non-refoulement refers to the concept that a refugee or asylum-seeker may not be forced to return to the place where their lives or their freedom were in danger. This is critical to the plights of refugees and asylum seekers because if they were to be sent back to their home country, their lives would be put in danger. Current policies surround refugees and asylum-seekers vary in the ways that they support or oppress this basic human right.

“The United Nations Refugee Convention requires that the US provide protection and safe haven to those facing persecution. By shutting the door to refugee admissions, whether temporarily or indefinitely, Trump's order flagrantly violates that core obligation... Article 3 of the Refugee Convention makes clear that all signatory states "apply the provisions ... to refugees without discrimination as to race, religion or country of origin ... While governments are responsible for designing their own refugee resettlement programs, these programs must conform to international obligations.” (Aljazeera, *All international laws Trump's Muslim ban is breaking*, 2017)

On January 27th President Trump initiated a travel ban on seven predominantly Muslim countries. Within the first seventy hours of this travel ban, green card holders, refugees, asylum-seekers, and permanent residents were all denied access to the United States at various entry points. Many were sent back to the countries where they had begun their journeys. The ban also put a stop on the processing of Syrian refugees. The United States

signed the 1951 Geneva Convention and as such is held accountable for actions surrounding refugees and human rights. This ban is in direct conflict with the basic rights of all people fleeing from the countries listed in the ban as well as non-refoulment.

Non-refoulment may also become questionable in the case of accused war criminals. War criminals, as stated above, cannot be afforded the political identity of refugee or asylum-seeker. Cases exist where war criminals have sought asylum in a secondary country under the guise of a non-criminal. Debate has arisen on what to do in this situation for two major reasons, the first being that when a person seeks these political identities they show well-founded fear for returning to their country of origin, this fact does not change once prior crimes have been unearthed. War criminals who have achieved beneficial status in their new countries would be unsafe and have a fear of persecution if they were to return (Justice in Conflict, *A Matter of Justice, Not Immigration: What to do with War Criminals posing as Refugees*, 2016). The second is that some countries do not allow extradition from within their borders. For example, the United States has a long list of countries, from Afghanistan to Uganda, that it does not have an extradition treaty with. Even countries that the United States does have a treaty with (Iceland, Switzerland, Venezuela, etc.) do not always comply with extradition requests (International Man, *The Best Countries for Your Escape Plan*, 2016).

Under the Geneva Convention refugees and asylum-seekers are afforded the right to move freely and settle in an area of their choosing once within the country that is granting them asylum. This right is sometimes misconstrued in the case of countries with

limited natural resources. If a country lacks resources, both political and natural, but is willing to take in refugees or asylum-seekers, it can create a refugee holding area. This “holding area” can vary according from country to country but is what we refer to as a refugee camp.

In theory camps are a temporary fixture, used for as long as the conflict or disaster lasts, and once it is over those housed within the camp can return to their homeland. This is not always the case as seen by the Dadaab refugee camp in Kenya. The camp was originally built in 1992, housing only 800 refugees, but grew to 18,000 in 2002 within ten years as a cluster of fifteen refugee camps were consolidated into four encampments in 1998. Dadaab, currently hosting over 150,000 refugees, houses a majority Somali population due to its proximity to the border and the raging civil war in the neighboring country. The camp hosts deteriorating conditions, extreme poverty, and vulnerability to bandits (UNHCR, *Analysis of Refugee Protection Capacity Kenya*, 2005). Originally set to close down in 2017, the camp has determined to stay open for the foreseeable future as Somalia is one of the seven countries listed in the Executive Order travel ban from President Trump and as such refugees and asylum-seekers from Somalia have one less place to seek refuge.



Figure 2: <https://www.wfp.org/photos/gallery/dadaab-refugee-camp>

Once a refugee or asylum-seeker has filed for their status in a particular country, that country is responsible for filing the seekers claim and offering the seeker liberty and security in whatever manner that may entail. When a refugee or asylum-seeker has received their political identity the rest of their family is automatically afforded the same status. This is used to try and keep families together. This automatic status is called derivative status and relies solely on the initial person who applied. If the person who received refugee or asylum status has the status revoked then the family unit as a whole loses their status as derivative refugee or asylee as well. The 1951 Geneva Convention outlines the basic rights which a refugee or asylum-seeker is entitled too. These rights include the right to education, the right to courts, the right to wage-earning jobs, as well as the right to property. In the United States, you are able to apply for a work visa if you are an asylum-seeker and you have filed your claim for asylum at least 150 days prior

(Learn About the Asylum Application Process 2015). If you have already received asylum status or are a refugee, you may begin working immediately and do not need to obtain a legal work permit (Asylum & the Rights of Refugees 2012).

Obstacles that refugees and asylum-seekers face

Many laws have been made to create a safe environment for refugees and asylum-seekers once they have escaped from forces that are impinging on their freedom as human beings, and their lives as a whole. This does not always mean that these laws successfully protect the basic rights of those who are relying on them. Port countries such as Greece act as holding pens for asylum-seekers and complaints of unsanitary conditions coupled with a lack of access to UN representatives add to the picture of an inhospitable atmosphere (Asylum & the Rights of Refugees 2012).

Holding centers are not the only things that refugees and asylum-seekers have to battle once they enter a country. Anti-refugee sentiment has hit an all-time high in areas of both the United States and Europe. Governors in 31 states in the United States voted to close off their borders to Syrian refugees (CNN 2015). While this may not bear any political backing, it does point to the large disinterest that more than half of the states in the United States have towards refugees and asylum seekers. Similarly, in Europe countries such as Hungary and Romania have openly tried to refuse the resettlement of refugees in their countries (Reporter and Post 2015). The executive order in January points to a large xenophobic ideology coupled with the election of President Trump, a

man who based his platform on promises of a wall, deportations, and anti-Muslim sentiment.

History of refugees in the United States

"Give me your tired, your poor, your huddled masses yearning to breathe free, the wretched refuse of your teeming shore. Send these, the homeless, tempest-tossed to me, I lift my lamp beside the golden door!"

Excerpt from "The New Colossus" by Emily Lazarus; inscription on the Statue of Liberty

The United States has a long history of interacting with refugees and asylum-seekers. The advent of the 17th century brought boats of religious refugees across the ocean. Eager to start a new life away from the eyes of the King of England, Puritans and Separatists alike found solace in the new colonies that awaited them in the new world. Fear of religious persecution and death drove them from their homeland and into the arms of a new nation.

Over the next four hundred years many would seek shelter in the new nation. A potato famine swept through Ireland forcing many to flee. England, Ireland's neighbors to the south refused to lend aid so the Irish were left with little choice; either remain in Ireland and starve or leave their homeland to start over new. The German Revolution of 1848 led political refugees to enter the United States from countries throughout central and Eastern Europe. This group of refugees would later be termed "forty-eighters" and

came to the United States from a variety of countries including German, Hungary, and the Czech Republic (Lich 2010). Throughout history, the world has been ravaged by conflict, disasters, and violence; forcing people flee their homes and create new lives in faraway lands. The United States was founded on the premise of becoming a safe haven for those fleeing persecution in their homelands, and as such to act as a beacon of hope for those looking for safety.

Feelings towards refugees in the United States

The United States has not always been the most welcoming of countries for those fleeing from hardship. A poll taken in 1938 by *Fortune Magazine* showed that over 67% of American's asked would rather "try to keep them (political refugees from Europe) out of the country than allow them entry into the United States" (FORTUNE Editors, 2015) Thirty years later American's were expressing opposite sentiments towards the "boat people" of Vietnam. The US Secretary of State at the time, Cyrus Vance stated,

"We are a nation of refugees. Most of us can trace our presence here to the turmoil or oppression of another time and another place. Our nation has been immeasurably enriched by this continuing process. We will not turn our backs on our traditions. We must meet the commitments we have made to other nations and to those who are suffering. In doing so, we will also be renewing our commitments to our ideals" (See Statement by the Secretary of State, Cyrus Vance, before the Sub-Committee on Immigration, Refugees, and International Law of the House Judiciary Committee, July 31, 1979, in Department of State, *American Foreign Policy 1977-1980*, (Washington, 1981, pp.989-941.)

The twenty-first century has led to a great deal of debate about the acceptance of refugees into the United States. Conflict in Syria, Somalia and Afghanistan have raised

the amount of displaced people in the world exponentially, reaching numbers as high as 65 million (UNCHR Figures at a Glance, 2015). With the rise of stateless people comes the need for nations to accept and shelter those without a home but it also forces eyes to be turned towards the cause of the displacement.

In 2015 United States was split with their opinions towards refugees with recent polls finding that, “By a narrow margin of 51 to 45 percent, the public approves of the Obama administration’s decision to accept more refugees.”(Galston, 2015) Time Magazine credits the anti-refugee sentiment to the idea that screening policies enacted by the United States may not be fully able to keep out the terrorists that may be pretending to be refugees (Alter 2015). After the execution of the travel ban on January 27, 2017, protests and rallies broke out at airports against the travel ban.

“Tens of thousands of people rallied in U.S. cities and at airports on Sunday to voice outrage over President Donald Trump's executive order restricting entry into the country for travelers from seven Muslim-majority nations. In New York, Washington and Boston, a second wave of demonstrations followed spontaneous rallies that broke out at U.S. airports on Saturday as U.S. Customs and Border Protection agents began enforcing Trump's directive. The protests spread westward as the day progressed.” (Fortune, *Muslim Travel Ban*, 2017)



Figure 3: Morillo; January 29, 2017

The video above shows one such rally that occurred in Boston at Copley Square on January 29th, 2017. Mixed emotions surrounding refugees and asylum-seekers permeate social media and news outlets and it is unclear as to how the country will progress in policies surrounding the populations. It is clear that for every action there is a strong reaction, as shown by the protests to the travel ban, and that the opinions of those in power in the government do not always speak for the masses.

Refugees and Asylum Seekers as patients

Prior to arrival in the United States, refugees must undergo an initial health screening.

“The examination is designed to identify individuals with health conditions that prevent entry into the U.S. as defined by public health regulation. ... The overseas medical examination also helps to identify physical or mental abnormalities, diseases, or disabilities serious in degree or permanent in nature that amount to a substantial departure from normal well-being. These “Class B” conditions require follow-up soon after arrival in the U.S.” (Refugee Health Technical Assistance, *Overseas Medical Exam*, 2011)

Tuberculosis, syphilis, leprosy, drug addiction, sexually transmitted infections and disorders with harmful behaviors are all considered to be inadmissible health conditions. These conditions must be treated before a refugee is allowed to enter the United States. In special cases a refugee may enter into the United States with one of these ailments but only with a special waiver. This initial screening is a refugee’s first introduction to the biomedical healthcare system found in the United States. Upon arrival, they must visit a doctor within three months for a domestic, secondary health screening.

“The purpose of the domestic health assessment is to ensure follow-up of any... condition identified during the overseas medical examination, to identify conditions of public health importance, and to identify personal health conditions that may adversely affect resettlement.” (Refugee Health Technical Assistance, *Health Assessment*, 2011)

This secondary screening introduces refugees to physicians and care providers who are directly aligned with the United States healthcare system. If the provider determines that follow up is needed, it is up to the patient to decide if they would like to return to see the physician or not. Once within the United States compliance to medical regiments,

consistency in visits, and overall health seeking behaviors fall into the hands of the refugees. They have successfully made the transition from refugee to refugee patient.

Asylum-seekers have a varied entrance into the role of patient. While they are not required to undergo overseas health screenings, asylum-seekers must undergo a health screening within the United States. Once the application process begins they must undergo the same domestic screening that refugees underwent at arrival. To add credibility to their accounts of persecution, asylum-seekers will often undergo specific assessments with physicians and mental health specialists to bolster specific accounts of torture. Due to the length of the asylum-seeking process, long-term adherence to a physician's recommendations may be more consistent than that of a refugee, as a judge may look favorable upon the biomedically compliant actions.

Defining biomedical health literacy

Health literacy is a term that is used to describe,

“(T)he degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions.”(CDC 2015)

The term can be used to illustrate the process of going to the doctor. When a person becomes sick they can either choose to seek medical attention or not seek medical attention. By seeking medical attention, they have a variety of options; self-treat, go to a pharmacy and ask for advice, or seek the help of a doctor or nurse. These decisions are influenced by prior knowledge that has been obtained through various sources. A person may be considered “health literate” when they are able to correctly make decisions

concerning their own healthcare. An example of this would be going to the doctor when you have a fever but not going to the doctor when you scratch your arm.

Observing how a person reacts to an illness is not the only way to determine if a person has high health literacy. Many tests have been created to examine health literacy and to quantifiably determine if a person is health literate or not. Health literacy tests include but are not limited to the Test of Functional Health Literacy in Adults, the Wide Range Achievement Test, the Rapid Estimate of Adult Literacy in Medicine and the Ask-Me-3 (Chew et. al 2009).

Other ways to determine health literacy can be as simple as determining the reading level of a person. According to Dr. Lisa Chew of the University of Washington,

“Persons with limited health literacy are those individuals who read at a sixth-grade level or less. They often misread the simplest materials, including medication bottles and appointment slips. Persons with marginal health literacy are those individuals who read between a seventh- and eighth-grade level. They are able to perform better on simple tasks than those with limited health literacy, but they have difficulty reading and understanding more complicated materials such as educational brochures and informed consent documents. Persons with adequate health literacy are those individuals who read at a ninth-grade level or above and who are able to complete successfully more tasks required to function in the healthcare setting” (Chew et. al 2009).

Health literacy in the simplest sense can be tied directly to the term literacy as defined above. This points to low health literacy being directly tied to levels of education which point to underlying structural issues directly working with or against a person’s ability to properly receive and understand medical care.

Importance of health literacy

Determining if a person has health literacy that is “passable” has become an important task for those in the healthcare world. Low or negligible health literacy has been linked to improper medication use and higher rates of rehospitalization among patients (Chew et. al 2009). In order to reverse the symptoms of low health literacy doctors, nurses, and others invested in the healthcare system have been striving to create ways to determine if a person has enough health literacy to adhere to the directions that are being administered.

There have also been initiatives that have been developed in order to understand and to increase health literacy in order to increase projected health outcomes. Project RED, for example, is research group that creates new programs and initiatives to lessen the amount of people who are being readmitted after being discharged by striving to increase their health literacy. The program uses a twelve-step protocol that covers everything from the preferred language of the patient and the caregiver to a call that is given three days after the patient’s discharge to determine if they fully understood the discharge plan (RED 2014). The research groups seek to educate the patients and their caregivers in order to lower re admittance rates in hospitals. This “re-education” is directly increasing the health knowledge of the patients and caregivers therefore directly increasing the health literacy.

Biomedicine and health literacy research

As stated above, health literacy is a primarily biomedical term and has been used to address primarily biomedical health issues. In biomedical literature, health literacy is looked at as a point of reference, if you have high literacy health outcomes are better; if you have low literacy health outcomes are worst. A great deal of biomedical literature addressing health literacy is trying to find different ways to quantify the literacy as well as new ways to improve the literacy. It is seen as a quantifiable staple that is found throughout health realms and as such has become commonly known. In this way physicians and researches may speak of and understand health literacy as concretely as they understand that a body has an internal temperature that can point to illness.

Anthropology and health literacy

“Results point to the need to assess knowledge, attitudes, and beliefs in specific subgroups experiencing cervical cancer disparities to identify target areas for health education. Study findings will be used to inform the development and pilot testing of health education curriculum modules for cervical cancer prevention.”
(Luque et al. 2010)

Anthropological literature tends to look at and analyze health literacy in the same way that biomedicine does. The quote above was taken from “Annals of Anthropology Practice” and discussed HPV in women that live in the southern United States. The article was designed to determine how these women thought of and understood HPV and cervical cancer. The researchers coined health literacy as a factor of the disparity in

cervical cancer numbers among Latina women as compared to Anglo-American women in the United States. The researchers concluded that in order to best help the women suffering from HPV, they would need to be educated therefore increasing their health literacy (Luque et al. 2010).

Health literacy points to one key component of healthcare in the world; there is a shared expectation that those entering the biomedical cultures, such as that of the United States, should develop an understanding of biomedical culture and develop the “correct” patient roles that are congruent with good health literacy. The literature shows that while other cultures may understand illness in a different way or treat illness using different tools, the only way that a person can truly be health literate is to learn the biomedical way of thinking and experiencing health. The desired outcome of increasing a person’s health literacy is for the outsider to become fluent in an insider’s way of thinking. An unconscious blind-spot has developed with the term health literacy, one that allows biomedicine to be seen as the ultimate good.

Healthworlds

I would like to argue that an uncritical understanding of health literacy has developed over the years. C. H Browner discussed his qualms of the medicalization of medical anthropology and warned that medical anthropologists may “go native”. If a medical anthropologist “goes native” they run the risk of simply accepting biomedical terms, illnesses, and categories without viewing them through a critical eye. Health

literacy is a term that is viewed with little to no explicit criticism. It may be that the term is only discussed in the biomedical realm but as such it merits a great deal of criticism due to its reference to health in only the biomedically defined terms. To discuss understandings of health within the asylum-seeking and refugee population, I would instead like to use the term healthworld. A healthworld,

“(A)cts both as a significant description of the empirical complexity of health beliefs and behaviours, and as a productive analytical tool in the study of society. This single concept encompasses several existing approaches (Hausmann-Muela et al., 2003) by simultaneously taking into account, in integrated fashion, both mind and body, person and society, life-world and system.” (Cochrane, J. et al. *Healthworlds: Conceptualizing Landscapes of Health and Healing*: 208, 2010)

This term seeks to emphasize the interlaying webs that connect all aspects of a person’s life and how they seek to determine health outcomes. By analyzing a person’s health based on a multiplicity of predictors overall livelihood can be elevated, and seemingly outside factors may be impacted by the services offered by the health sector.

Healthworlds originated from fieldwork conducted by James Cochrane and Paul Germond in Lesotho. While studying the relationship between religion and health, the researchers noted that the two terms in Sesotho, the local language, were not interchangeable, but could not be defined without the use of the other term. This complexity of terms turned the researcher towards a Sesothian term that encompassed “life” and “health”, *bophelo*.

“Bophelo can be conceived of as existing in six overlapping and intersecting socio-spatial configurations: the person, the family and homestead, the village, the nation, the religious realm, and the earth... Thus, to fully exist, bophelo must

reside in all of these socio-spatial arrangements simultaneously.” (Cochrane, J. et al. *Healthworlds: Conceptualizing Landscapes of Health and Healing*: 209, 2010)

Trying to find a term in the English language that could encompass the full nature of *bophelo* proved to be difficult. Healthworlds was the result of this lack of existing terminology and was set to define the complexity that surrounds a person’s conception of health and healthcare.

Ethnomedicine

In his work *The Scope of Ethnomedical Science*, Horacio Fabrega Jr. introduces ethnomedicine as, “The study of medical institutions and of the way human groups handle disease and illness in light of their cultural perspective” (Fabrega, 1977: 201). In other words, Fabrega uses the term to encompass how a certain group of people understand illness and how they treat illness based on a culturally appropriate response. Ethnomedicine is firmly ingrained and created by the groups in which it is found, illness therefore, is not an objective term.

“Again, groups differ as regard to and mode of explaining the basic distinction between illness and non-illness” (Fabrega, 1977: 203)

Fabrega’s elucidation of the cultural basis of illness and medicine point to the idea that there is not simply one way to think about health. To be healthy is different in every culture and the formulation of this basis of health may deviate greatly from culture to culture.

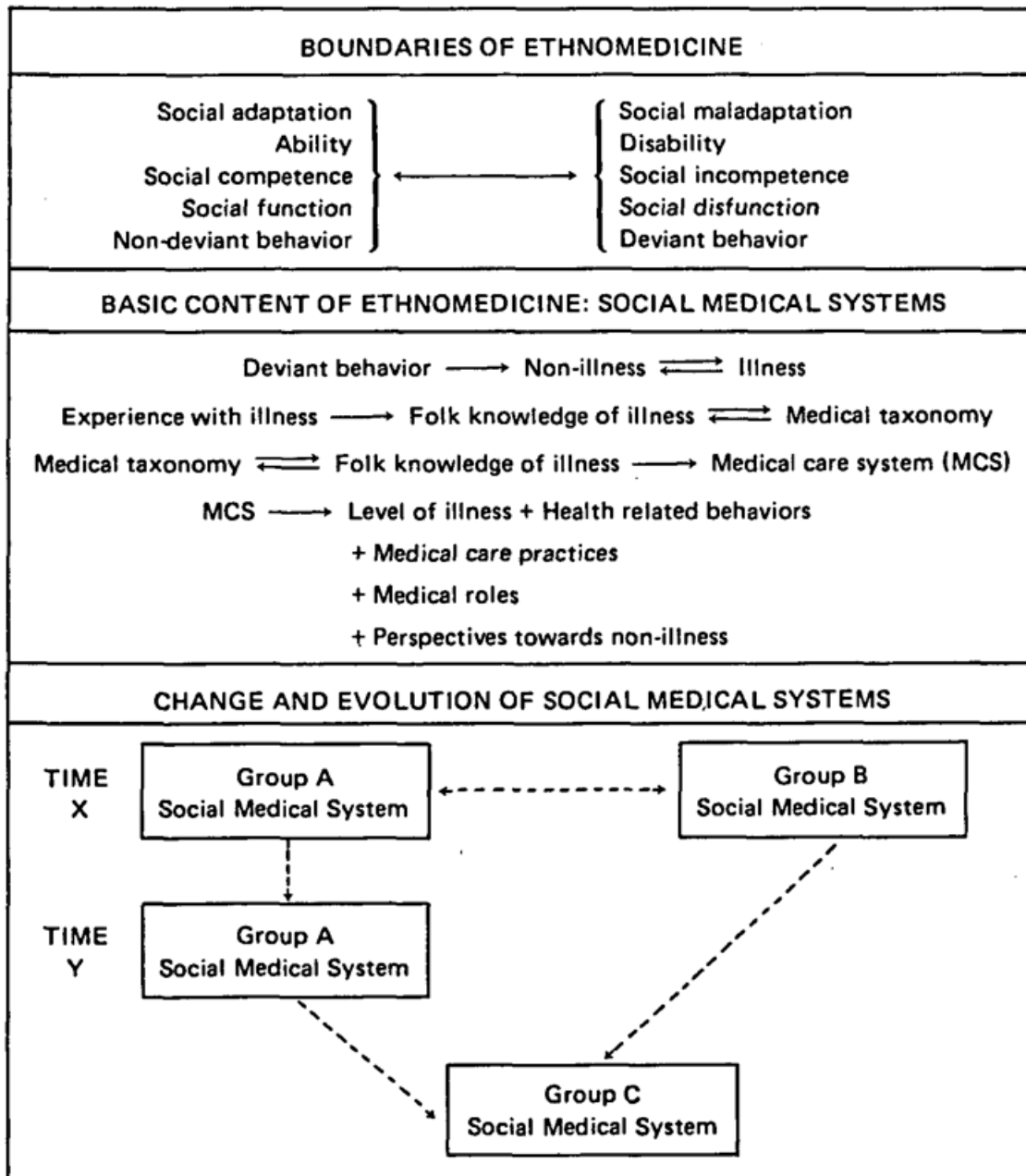


Figure 4. Basic concepts and principles of ethnomedical science.

To illustrate the fluidity and complexity of ethnomedicine, Fabrega has developed the chart above which shows the boundaries, content and evolution of ethnomedicine within a given culture.

Ethnomedicine encompasses the abstract nature of how a community views and understands health and illness in a given setting. In combination with healthworlds, a more holistic understanding, and discussion of, well-being has come to light.

Conclusion

The following analysis draws on the intricate relationship between refugees and asylum-seekers and their introduction to and navigation of the United States' healthcare system. Throughout the discussion, concepts above may be directly or indirectly referenced but should be used to foster deeper thoughts on how the biomedical system both limits and assist the health-seeking journey of the populations.

METHODS

Initial Design and Participant Population

I began my research design with high hopes of doing participant observation at a Refugee Clinic at the largest health safety net hospital in New England. The clinic acted as a primary care clinic for refugees and asylum-seekers in the greater Boston area and aligned exactly with my desire to look at how refugees navigated the healthcare system of the United States. The site would allow me to interact with the population in a clinical setting while also observing how they interacted with medical professionals. I would also be able to observe how physicians interacted with their patients, how they would talk about medicine and describe illness to patients from around the world. Coupled with the participant observation I planned to recruit for unstructured interviews from the Clinic. I choose unstructured interviews because it would allow me to follow a general guideline of concepts or questions that I am interested to hear about, but it allows for conversation to continue naturally as well (Bernard, 2005).

Throughout the spring semester I was in contact with the Clinic, trying to create a research design that fit well with the goals of the clinic. The clinicians were concerned that clients would not have time to talk to me or that they would not want to. Barriers such as language and confidentiality ultimately led me to change the research design and focus on other sites to gain access to the population. Fortunately, I was able to create a research design for another refugee specific Center in the same hospital as the clinic, this

served as a mental health clinic that specialized in victims of primary or secondary torture. I had been volunteering at this site for over six months and had initially been told that I would not be able to recruit there. I spoke to a staff member in the Spring of 2016 and they said that they would help me create a research design that would be able to work in the “Place” . My design consisted of me continuing my volunteering at the “Place”, continuing to work as a refugee patient navigator but also allowing me to interview clients which the staff deemed acceptable. By continuing my volunteering, I was still able to interact with the staff and continue my participant observation. For the interviews, the staff would tell certain patients that they deemed fit about my research and after they had broached the subject they would allow me to try and recruit the clients to be interviewed.

Along with the “Place” I was able to add the HELPING CENTER as a site for recruiting potential participants. Similar to the “Place” , my gate-keeper would act as the recruiter for my research. The gate-keeper would contact clients that she thought would be good for me to interview and set up a time and place for us to meet up and talk about health. As I continued to talk to organizations about their work with refugees and asylum-seekers in the Boston area, I became increasingly interested in one organization. Ministry for Refugees helped to place asylum-seekers in housing until they were able to start working and get on their own feet. I was interested in this site due to how it differed from my other two sites. Ministry for Refugees would allow me to volunteer and utilize participant observation by observing and interacting with refugees, asylum-seekers, and staff outside of a medically based setting and in a faith based setting.

Overall I hoped to interview about six to ten participants at the “Place” and about four to seven participants through the HELPIING CENTER. My inclusion criteria for participants consisted of being either a refugee or asylum-seeker and being over 18 years old. I initially had placed the stipulation of being comfortable speaking in English but for the HELPING CENTER, my gate-keeper agreed to act as a translator. I used opportunistic sampling due to the fact that my gate-keepers were choosing who I would be able to talk to and then letting me try and recruit for participation in my research.

Participant-observation site & Access

I began my internship at the “Place”, with qualms over who I was as a person. As a twenty-something female from the Southern United States, I had little in common with many of the clients at the “Place” who I would soon be interviewing and interacting with. I was never forced to flee from my home, fearful for my life. I was never forced to live in a country where I did not speak the language or understand the cultural norms. I had traveled a bit and understood what it was like to experience culture shock, but I always knew I could go home. My participants had been completely stripped of a home, and even though they were grateful to be safe in the United States, many still yearned for their own country. At the “Place”, I acted as a refugee patient navigator, a position that allowed me to grow in my understanding of, and compassion for, the refugees and asylum-seekers that graced the hallways. My position as a refugee patient navigator allowed me

to engage in participant observation as well as actively witnessing the experiences of refugees and asylum-seekers in an outpatient mental health clinic.

A typical day in the life of a refugee patient navigator, or RPN, as we were referred to by the social workers and psychiatrists at the “Place”, was hectic and unpredictable. These days were full of emotions, confusion, but mostly a kind of happiness that seeped through the hallways. Upon arrival at the “Place”, I would first make my way to the RPN room where a call log sat on the large circular table, indicating who was coming in and which doctors or social workers the refugees and asylum-seekers, or clients as we referred to them, were seeing that day. RPNs were in charge of “starting off” an intake. An intake was the nickname given to the first full meeting that a client (refugee or asylum-seeker) had with a service provider at the “Place”. First-time clients would arrive and an RPN, like myself, would greet them in the waiting room, I would offer a hot beverage or water, all while introducing myself and the new client to the basic function of the “Place”. After a quick introduction, I would ask the new client to a separate private room to begin the intake process. Once a client and I were situated in the room the I would go over what services the “Place” offers, from dental care to support groups.

The initial intake process was one in which I learned a great bit about the refugee and asylum seeking population as a whole. Questions and responses varied from client to client but I learned how to approach questions with the population. When talking about support groups I would say that we already had groups assembled and people going so they would not feel alone in wanting to talk to others about what they had gone through.

When talking about assigning a primary care physician I would always make sure to mention that these doctors would be able to help them get medicine, and that it would be free with MassHealth insurance plan that we would help them apply for. Most importantly, when talking about mental health referrals and basic medical exams, I would be sure to emphasize the importance of these examinations in the formation of an affidavit and a testimony that would hopefully allow the client to gain asylum status in the United States, establishing from the beginning that, for the “Place”, the acceptance of biomedical surveillance is part of the process of affirming their refugee or asylum status.

These meetings were often emotional in ways I did not anticipate. A client once informed me when we had taken seats facing each other in a social worker’s office, that sitting like we were reminded him of being interrogated in his home country, reminding me that many asylum-seekers were eligible because of torture that sometimes occurred in settings that could mimic the interview “esque” feeling of an intake. Even while I was trying to help someone access services, I might inadvertently say or do something that could remind them of past trauma. After going through the list of services offered at the “Place”, I would go through two separate scales (surveys) with the client, one evaluating post-traumatic stress disorder symptoms and one evaluating depression symptoms, based on U.S. psychiatric criteria. These scales asked a wide range of questions varying from inquiries about sexual desire to regrets in the past, from suicidal thoughts to being “jumpy.”

The first time that I was exposed to the scales I felt instantly uneasy. Who was I, a graduate student with only basic trauma informed mental health training, to be asking

such serious and personal questions, questions that I would feel uncomfortable answering myself. It was after I began running the intakes that I realized my positioning as an RPN allowed the clients to look at me as an extension of the social workers and physicians that worked at the “Place”. I was not just some random volunteer that would shuttle them around the hospital but a person that could help them get insurance, I was a friendly face that they could talk to about their favorite activities, a person that gushed at the pictures of their homelands.

As an RPN I was a vital part of the “Place” and this position allowed me to ask the intake scale questions without feeling like I was intruding on their personal life but instead I felt as an active participant in their journey of mental and physical healing. After baring their souls to me or another RPN, clients then go to see their newly assigned case worker for the first time, to continue their intake by discussing their history and their primary or secondary accounts of torture. As an RPN, I was also responsible for taking the clients to food pantries, patient financial services, the pharmacy, and anywhere else that the client may need to go in or around the hospital.

These responsibilities were among the best and most meaningful interactions that I had with clients at the “Place”. Patient financial services is the area of the hospital where low-income patients go to apply for state-sponsored health insurance or sign up for payment plans. In the case of many of the “Place’s” clients, this was a turning point -- getting health insurance meant that they were able to access free care in the hospital, free medicine from the pharmacies, and had one less thing to worry about when it came to entering the United States healthcare system. Many times, I spent hours at Patient

Financial services sitting with clients in the waiting room, listening to their stories about their experiences in the U.S., how they liked the weather, and whatever else they felt comfortable talking about.

This experience in the RPN position allowed me to develop and hone my skills interacting with the refugee and asylum-seeking population. I was taught how to literally *navigate* conversations, avoiding speaking of things that may trigger traumatic memories while still being able to keep a conversation going. I learned that when a group of Somali women ask for tea it means bring the whole box of sugar. I learned that the coat closet, which was full of donations from local churches and nice people, is known by the clients as “the shop” and even though most of the (recently arrived) clients were unprepared for the cold Boston winter, many refused to take more than one jacket because “there are people that need it more than me.” I learned that to be strong and silent when all you want to do is break down while someone is crying about the horrors they endured, is perhaps exactly what a person needs. Most importantly I learned that strength and resilience is a trait that permeates through the population, that even though people have literally been through hell and back in their particular circumstances of primary or secondary torture, they are fighting and determined to survive and create a life for themselves in the United States.

Along with my internship I volunteered at the Ministries for Refugees, or MIR, a small non-profit, faith based, organization that helped to give aid to the asylum-seeking population in the Greater Boston Area. While volunteering at MIR I did not necessarily have a set role, one day I would be making copies, and the next day I would be helping

interview potential clients that needed services. While at MIR I was able to work with the executive director. Interacting with a woman who had worked with refugees for decades was an amazing opportunity. She would tell me stories of her life and we would discuss ways to make the organization better by extending services in new ways to the clients

Both MIR and the “Place” acted as amazing sites for participant observation. Through my internship at the “Place”, I was able to gain rapport and confidence with the refugees and asylum-seekers that came to the “Place”. My participant observation at MIR allowed me to gain a completely different perspective of the health of refugees and asylum seekers due to my interactions with the director of a faith based organization instead of clinicians.

Recruitment Sites

I volunteered at the “Place” for nine months before I brought up the possibility of recruiting clients for interviews at the site. When I initially began volunteering at the “Place” the project coordinator told me that I would not be allowed to do any research at the site so I began searching for other sites to recruit for my research. In April I again broached the topic of possible recruitment at the “Place”, and with the help of one of the social workers, I was able to create a recruitment protocol that aligned with the ideals of the staff.

Along with the “Place” I was able to reach out to the HELPING CENER with the help of my advisor. Through my advisor’s connections, I was able to meet with the

program coordinator for the Lynn office of the HELPING CENTER, and discuss the possibility of recruiting clients of the organization for interviews. We discussed an interview guide that she felt comfortable with and she agreed to act as a translator for the clients that did not feel comfortable using English.

Recruitment

At both the HELPING CENTER the staff acted as gate keepers for my interviews. At the “Place”, staff would approach me with clients that they deemed appropriate to be interviewed. They would introduce my research before or after their appointments with the clients and if the client was interested the staff member would let me know. I would then be able to describe my research and ask if they would like to be interviewed. At the assistance center my gate-keeper would simply email me saying that they had a client that they thought would be good for me to interview. They would then give me a time and place to meet the participant for an interview. Using a gate-keeper to help me recruit for my interviews was a catch twenty-two, on one hand, I knew that the participants that I was able to interview were interested in talking about health. On the other hand, I was not able to reach out on my own to try and recruit participants that may be interested if my schedule did not align with that of the both gate-keeper and the participant.

Interviews

I was able to interview four refugees/asylum-seekers throughout my fieldwork. Among them, three were female and one was male. All of the participants that I interviewed were from Africa and had arrived in the United States in a time frame ranging from 15 years to 2 months ago. The interviews ranged from 20- 40 minutes and all of my interviews were done in person. I had one interview in which a translator was in the room while I conducted the interview.

Limitations of the sample

The major limitations of this sample lie in the vulnerability of the population as a whole. While many agree that refugees and asylum-seekers are a strong group of people they are seen as paradoxically vulnerable and providers often do not let outside researches have access to them in clinical settings. I was fortunate enough to have a strong relationship at the “Place” but it took me a great deal of time to gain permission to interview at the site. I also did not interview as many participants as I wanted and felt that my data was not close to saturation. This low number was due in part to own hectic schedule but also to factors outside of my own control. I had days where I would show up at the “Place” with permission to talk to two or three clients, then when their appointment time came they potential participant would not show up. This could be due to a variety of factors; it may be raining out which often deters people who are taking public

transportation, it may be the end of the month and they had run out of money on their Charlie cards, or they may have just simply not wanted to make the journey to the “Place” that day.

Data Analysis

To analyze my data, I used a combination of modified grounded theory, phenomenology and critical medical anthropology. Modified grounded theory seemed like the best way to approach my data because I did not want to come in looking at the interviews or field notes with preconceived ideas of what refugees and asylum-seekers thought of health. I wanted to be able to build upon what the data was telling me. I used phenomenology because I was looking and trying to build a picture of how my participants experienced healthcare and created their own health care “world” (Charmaz, 2011). Phenomenology allowed me to analyze my data by reading through and enabling me to look at how each experience was shaped. I felt as I needed to look at the data in a way that put it in context of the surroundings. Critical medical anthropology was the best way to do this due “its commitment to embedding culture in historically delineated political-economic contexts” (Singer 2004). Refugee’s and asylum-seekers are coming from areas that are politically charged and dangerous, this must be taken into effect when looking at their actions and comments regarding health.

Within a week of each interview, I made sure that I had the material transcribed and coded. I used a naturalized transcription method and made note of specific aspects of

the interview such as long pauses and deep breaths. Transcribing in this manner allowed me to see anything that I may have missed while I was conducting the interview. I noticed pauses that may have indicated participants were uncomfortable as well as points where I should have probed more. I used naturalization because it allowed to not only remember the words but to remember how there were said as they are both important in analysis of data.

I decided to hand code the transcripts, picking out major themes and concept all the while keeping in mine modified grounded theory, phenomenology, and critical medical anthropology. I wanted to build a multidimensional understanding of what each participant had said and also of what I had observed. By hand coding the transcripts I felt like I was able to pick out little details from each line that led to larger themes, it also allowed me to physically compare similarities and differences within the data. The codes were used to create larger themes from the data which I will discuss in further chapters.

The Sites

“For a long time, one of the characteristic privileges of sovereign power was the right to decide life and death.”(Foucault 1990:135)

After World War II, the world’s major powers came together and collectively decided that it was their responsibility to take care of refugees. They came up with a code of conduct surrounding the population, basic rights that refugees would be afforded. These basic rights evolved throughout the years and have been defined and redefined. For example, according to the Sphere project, a humanitarian aid charter with specific guidelines for helping refugees, a person is allotted a minimum 7 liters of water a day (The Sphere Project, 2011). These guidelines are not arbitrary and do offer a great deal in increasing the lives of refugees or displaced people in emergency settings. The governments, by offering their care to refugees and asylum-seekers, are exhibiting, maybe unintentionally, their power over the lives and deaths of these populations or as Foucault claims,

“(T)he ancient right to take life or let live was replaced by a power to foster life or disallow it to the point of death.” (Foucault 1990: 138)

This power over the lives of the population, or biopower, combined with a moral economy allow for an environment that allows organizations aiding refugees and asylum-seekers to develop in highly pre-specified ways.

A moral economy is the term that is used to define the idea that the economy is closely tied to morals or “fairness”. E. P. Thompson defined this term while discussing food riots in 18th century England. Peasants rioted over-priced bread refusing to pay

market based prices instead insisting on fair prices (Thompson, 1971: 76-136). The term moral economy was further developed by Sarah Willen in her discussion of the moral economy of unauthorized migrants in Israel. She furthered the concept of moral economy to show how it engages

“(A)n urgent scholarly concern: a desire to make sense of complex human dilemmas and predicaments, of various kinds and at varying levels of analysis, by training an empirical gaze on the conjunction among political processes, moral commitments, and the lived experience of individuals and groups.” (Willen 2015: 74)

Willen furthers this desire by breaking down the concept even more by situating moral economies as something that

“(I)nvolve historically and culturally particular constellations of value and affect, memory and expectation. Within any given local moral economy, different stakeholders and groups of stakeholders reckon such matters as inclusion and exclusion, deservingness and undeservingness, in markedly different ways.” (Willen 2015: 72)

Her discussion of moral economy encompassing unauthorized migrant workers parallels the way that organizations in the United States combine morals and economy. An example of this can be seen in the way that money is allocated, or donated, to certain organizations based on these groups doing the right, or the morally correct thing. Based on a moral economy, refugees and asylum-seekers are valued in a specific way, ranked higher in deservingness than other immigrants or even some citizens. Refugees and

asylum seekers are historically embedded in the moral conscious of the world due to a multitude of large scale, and largely publicized international crisis. Victims of the Holocaust, Rwandan genocide, Armenian genocide, Balkan wars, Vietnam war and the Somalian war have been proven to be deserving, due to their distinct suffering, by governments worldwide and therefore have given moral value to refugees and asylum-seekers as a whole. Due to the persecution that these people underwent, they are automatically assumed to need more help in their new homes, drawing on the doing the right and fair thing, agencies and organizations have developed to fill this niche of care.

The HELPING CENTER

I have been sitting in this classroom for almost an hour now; it's been at least twenty minutes since the motion sensor triggered overhead lights have turned off. The soft lull of the window based air conditioning unit is starting to lull me to sleep and I have to fight to keep my eyes open in the just warm enough room. The large windows to my right offer a view of a busy street, busses fly by as kids laugh loudly, enjoying the freedom of their summer break. I glance up at clock above the chalkboard one more time, it has been another five minutes and the person that I am supposed to interview still hasn't arrived.

As I put the finishing touches on the trees that I am doodling in my notebook, I hear voices outside the door. I look up and smile as a small woman dressed in a dark grey dress and bright orange scarf walks into the room. My first interview participant has arrived. (Fieldnotes June 2016)

The HELPING CENTER is a grassroots organization boasting multiple offices throughout the greater Boston Area. Serving primarily a Sub-Saharan African population, the HELPING CENTER offers resettlement assistance as well as education, outreach and counseling services for the refugees and asylum-seekers. Admittedly out of all my research sites, I spent the least amount of time here and my interactions were limited that of Asha, the woman that I interviewed, and my gatekeeper, the Program Coordinator for one of the offices.

Throughout my fieldwork, I visited two of the main offices that the HELPING CENTER worked out of. The first location was inside of a larger healthcare building. The building stood out on the suburban street where the it was located and boasted a large iron fence that encircled the parking lot. The address on the building did not match the one that I had found on the website so I entered the lobby simply to ask the receptionist for directions to the HELPING CENTER. It turned out I was in the correct building and as I gave the woman working in the front desk my drivers-license I glanced at the directory and couldn't help but notice how many different offices the building hosted. Ranging from medical offices to lawyers, the building offered a range of services that I was not used to finding in one location.

I made my way up to the third floor and wandered around the hallways until I reached a door with a sign labeled HELPING CENTER. The door opened to a large open area with a block of four cubicles directly to the left and a desk in the center. As I glanced around I noticed how bright the room seemed even though it lacked windows. The room had a distinct earthy smell and boasted signs and posters detailing events for refugees. As

I walked to the program coordinators desk I observed how wide open the offices seemed, the cubicles were all open and the desks were out in the open, not located in separate rooms.

When I first introduced my research to the program coordinator at the HELPING CENTER, we discussed the services that were offered at the center. She was excited to tell me about the mental health services that they were offering their clients. English classes were offered weekly and she said that they would possibly offer a good place for me to recruit participants to be interviewed. Unfortunately, I began my research just as Ramadan began and as the classes were on Sunday, and the clients of the HELPING CENTER were predominantly Muslim, classes were suspended until Ramadan was over.

The HELPING CENTER cares for their clients through a seemingly regular model. They offer resettlement aid, helping refugees find housing. They offer English classes, a way to help their clients integrate and thrive in a predominantly English speaking state. Mental health services are also offered through the HELPING CENTER. While seemingly normal for a refugee specific organization, each element held something that was specifically constructed through the HELPING CENTER. When I initially showed the program coordinator my interview guide she asked me to add some questions pertaining to mental health as she was curious as to what her clients would say about the subject. They had integrated mental health services into the organization but as shown by her distinct request, it was unclear how the community understood mental health or how they looked at mental healthcare.

The HELPING CENTER's website offers a much broader view of the organization as a whole. They list services such as job-skills training, translation services, citizenship help, health care education, community counseling and many other services that were not explicitly stated in my conversations while at the office. These services offer a holistic care model that spans not only physical and mental well-being but also focuses on the "non-health" based areas of a refugee's life. The center offers help with jobs, education, social stigma, language barriers, resettlement and so many more unnamed aspects. This personalized approach to care was portrayed to me as I spoke with the program coordinator and she received a phone call. She quickly explained to me that she didn't usually keep her phone on but one of her clients was having a hearing of sorts that day and she wanted to be able to assist with anything that the client may need. This above and beyond model of care cannot be defined by a website or by a few short visits to an office building. The HELPING CENTER's model of care is formed from a social service point of view that focuses on "non-health" priorities. These intangibles are directly related to health and healthcare and as such the HELPING CENTER has bridged the gap implicitly through "non-health" but also explicitly by offering mental health services.

The moral economy that has developed for the HELPING CENTER is focused on the concept of community support and mutual cooperation. The organization was originally intended to be a mutual aid agency for Somali women and children, created by Somali women. In this case, it benefited the women that were creating and organizing the

services because by helping others in their community they were strengthening their community as a whole and creating better lives for themselves.

The ideal client for this organization is seemingly broad; the HELPING CENTER advertises aid services for refugees, asylum-seekers, asylees, immigrants and other members of the community. Although broad, an overview of the services offered point to more established refugees or community members as being those that benefit the most from services such as English classes, mental health services, job searches, and other education opportunities.

Ministry for Refugees

RING! BRING! BRING! I jump out of my seat of my corner desk where I had been working on my flyer for English classes. As I look up at Robin I finally realize that the fire alarm is going off. She glances at me and gives an exasperated sigh, "They go off once a week! Come on, might as well start walking down the stairs." We shuffle out of the office room filled to brim with paperwork and bookshelves and make our way down the five steps. The whole building seems to be following suit and as we make our way to the sun soaked sidewalk I glance around and notice that all of the buildings on the block seem to have the telltale blinking lights of a fire alarm going off. To my right is the owner of the Middle Eastern Restaurant and to my left is the friendly woman who always waves as I park in front of the Korean restaurant. As the sidewalks fill I hear a variety of languages, Robin and I seem to be the only ones speaking English. As we sit and wait for

the ringing to stop, Robin begins asking me about the pictures of religious sites that I have been compiling for a poster we want to make. “Did you find the picture of the temple in Prague? It would look nice next to the picture we have of the National Cathedral.” (Fieldnotes July 2016)

The Ministry for Refugees, as stated previously, is a faith based organization that offers aid to refugees and asylum-seekers in the greater Boston area. I spent two days a week working with Robin, the Executive Director, at the central office for the organization. Located in a sprawling town on the outskirts of Boston, the offices location was less than a mile from the train stop and located on a busy central street. Located on the third floor of a homely office building, the Ministry for Refugees spanned two medium sized office rooms. The main room was composed of three desks surrounded by bookcases of paperwork. The second room hosted a long table with up to ten chairs situated around it at any given time.

My initial plan while working at the Ministry was to work as an English teacher. I would help lead classes through a program that Robin had been given special access. Unfortunately, the classes did not pan out as originally thought, we had some students come in for an initial testing to determine levels but never return for a real “first” class. Others simply did not show for their appointments. Eventually my role began to morph and I was put in charge of small tasks, helping to translate a flyer for English classes, creating a new poster to place on the wall, helping to plan events. My day was often punctuated with long talks with Robin about any and everything. From the political

climate to different kinds of food, from her time abroad to being a grandmother our conversations were never boring.

Robin is a Reverend for the Episcopal Church with over thirty years of experience working with and helping refugees. Her work with the population is based on a spiritual and faith centered focus that is rooted in the idea that trying to manipulate a person's faith in a time of crisis is immoral and unethical. Instead of forcing a refugee or asylum-seeker to seek a certain religion in order to receive care, the Ministry for Refugees is dedicated to placing refugees and asylum-seekers in faith based communities that they have chosen for themselves. By placing a person in a faith based environment that they feel safe in, they are offered at least one sense of normalcy, one familiar ideology in a new country.

The Ministry for Refugees offers four main services; clusters, English classes, job training, and spiritual caregiving. Clusters are a group of congregation members within a given geographical location. They work together to take in clients and offer them housing and support while the clients are unable to work due to work authorizations. Both English classes and job training offer chances for clients to be enculturated into the workforce of the Boston area. Offering courses in English allows for a refugee or asylum-seeker to have a sense of independence, to be able to get around on their own without the aid of someone else. Job training allows for a refugee or asylum-seeker to enter into the working sector legally after receiving work authorization. These services, though not directly tied to health, help to allow clients to feel a sense of ease and allow for an easier navigation of the healthcare system in Boston.

Spiritual caregivers are a position that I never explicitly ran across while doing participant observation at the Ministry for Refugees. That is not to say that the caregivers do not exist as I was unable to attend any board meetings throughout my allotted research period. Spiritual caregivers, as defined by the organization's website, are a people from varying religions, cultures, and speak different languages. These volunteers seem to be called upon when a person is detained, either upon entering the United States as an asylum-seeker or when they are being processed for deportation. In these facilities, volunteers are often unable to do anything but listen to what the detained person has to say. The experience of going and listening to a detained person's story could be described as bearing witness to the pain and suffering while also offering a humanizing effect for the person telling the story. Didier Fassin describes humanitarian action based on an aspect of the term humanity,

“(A) sentiment that manifest an individual's gesture of humanity toward fellow humans who are suffering or in danger- a sentiment that gives a concrete sense of belonging to the human species. This concept has been established in contrast to others that either imply distinctions among human beings or promote indifference to distance others” (Fassin 2007: 462)

Bearing witness is the Ministry for Refugees' form of humanitarian action, a humanizing gesture, to work to give a sense of belonging to a population that has been greatly “othered”.

Ministry for Refugees began as an organization centered around the spiritual caregiver model. They evolved to offer more services for clients who were not being held

in detention centers. In practice, I have seen how effective this organization is at taking care of the clients within their sphere. I have seen clients come in and seek care at the “Place” and as they write down support groups where they are receiving services, Ministry for Refugees pops up as an organization that is able to offer a service that is greatly needed, housing. The services offered by the Ministry for Refugees come from a faith based core and evolve to take care of and support refugees and asylum-seekers as they struggle work to develop a sense of being in Massachusetts. Discussion of care with Robin portrayed how deeply she understood and valued the relationship between faith and support for this population. The organization’s reliance on faith centered communities to fund and house clients reinforces this relationship while also portraying the extent that the organization has grown to fill the needs of refugees and asylum-seekers in the area.

As a religious based organization, the Ministry for Refugees is focused on caring for the spiritual welfare of the community that it serves. In particular, each cluster of religious groups is focused on matching each refugee or asylum-seeker with a religious community that matches their own. A religion creates a sense of community for everybody who claims that faith; a Protestant from California is part of the same community as a Protestant from Cambodia. They are joined together under a larger belief and as such the clusters allow for the community to take care of their own. Similar to the moral economy of the HELPING CENTER, Ministry for Refugees is based on the concept of supporting members found within their own communities, strengthening all the members creates a stronger overall community.

The clients that the Ministry originally set out to help were detained persons. The organization evolved to serve asylum-seekers, refugees, and other immigrants in the greater Boston area. In order to receive assistance with housing though, one must be an asylum-seeker without work authorization. This person must not be working under the table and if they are found to be doing so they are kicked out and services are discontinued. For other general services such as English courses refugees, asylum-seekers and other immigrants are welcome.

The Place

I arrive at the seventh floor with my stomach in knots. I quickly glance over my outfit to see if I look presentable; “Professional” closed toed flats with a pair of nice “work-place” pants and a button up shirt. As I find the waiting room for the “Place” I glance around nervously. I have never been to a mental health clinic before and I cannot help myself from glancing around trying to take in every detail of the room. The media does not portray these clinics correctly from what I can tell. The waiting room is void of people but full of colorful artwork and signs written in different languages. I walk closer to one colorful painting in particular and notice that the seemingly picturesque scene actually depicts violent acts and shows settings such as villages or large cities. This does not match my prior notions of what a mental health clinic should look like based on media descriptions. “Meghan?” I hear my name being called and as I walk through the

open door to the director's office, I take one more look over my shoulder at the colorful painting and then my interview began. (Field notes August 2015)



The waiting room at a doctor's office can tell you a great deal about the experience that you may have when you see the doctor. The waiting room at the "Place" paints a vivid

picture of the environment that the “Place” hopes to foster. Signs written in a variety of languages point to the inclusivity of the clinic allowing all to read the messages written throughout without feeling helpless or if a person is unable to read, a sense of familiarity in letter. It also points to the diversity of the clientele, a clinic that serves mostly English speakers would not think to add a sign written in French or Arabic.

What the clinic staff chooses to hang up within a waiting room also speaks to the purpose and focus of the office. In the case of the “Place”, a picture is hung that depicts human suffering in a multitude of forms. The picture was created by patients of the clinic and depicts scenes that mirror the trauma that they had experienced in their lives before arriving at the clinic. Trauma brings patients to the clinic both directly and indirectly. Directly, trauma can have negative mental health effects on a person, leading to post traumatic stress disorder, depression and anxiety. The “Place” is a mental health clinic that treats mental illness. Indirectly, trauma leads to a person’s need to flee their home countries and their entrance into the United States as undocumented and needing to apply for asylum. The “Place” is a key entrance point into the asylum-seeking process in the greater Boston area. Finally, trauma is the primary factor that points to mental illness as being the most important aspect of refugee and asylum-seeker healthcare.

The “Place” is located in a large health safety net hospital in New England and boasts a holistic approach to healthcare for refugees and asylum-seekers. A mental health clinic that deals exclusively with victims of torture, the clinic boasts mental health care while also offering referrals to primary care physicians, dental care, specialists and lawyers. Along with psychotherapy and psychopharmaceutical care, the “Place” offers

case management, job readiness training, resume building workshops, leadership workshops, English classes, food pantry access, a coat closet, and assistance with transportation. The “Place” recognizes the various needs of a refugee or asylum-seeker in the greater Boston area, and works within the limits of a clinical setting to provide for these needs.

Within the walls of a hospital, it is often assumed that physical or mental health or wellbeing are the top priorities. Within the “Place”, priorities shift in different ways to align with the desires of the patients which seek the care of the staff.

The foundation of the Place’s moral economy is based on the organization’s origin. The Place began as a mental health clinic that sought to link medical and legal care. These primary services have evolved to create an all encompassing approach to care but speak to the deservingness of this population and the general consensus that they suffer from psychological needs and legal needs. This organization ideal client is a non-citizen who is a victim of primary or secondary torture. This client has been traumatized and needs mental health care. The organization is setup to work hand in hand with lawyers who represent these client’s asylum claims in court

Conclusion

The origins of these three organizations do not fit they role that they currently fill. Ministry for Refugees began helping solely those in detention centers, the Place began by focusing on psychological support and legal needs, and the HELPING CENTER focused

solely on Somali women and children. These organizations have shifted their functions due to funding and observing greater general needs. They also interact fluidly in a large ecosystem of support systems. The HELPING CENTER can send people to the Place, and the Place can send people to the Ministry for Refugees. By utilizing each organization, a client may receive all the help they may need. The organizations all work within the biopolitical regime but find creative and distinct ways to break out and help the individual at their own level. The power over the lives of their clients is not used to corral people into a certain way of living but instead allows the clients to pick and choose the way that they navigate a new life in the Greater Boston area.

Stories

The organizations working to aid refugees and asylum-seekers in the greater Boston area are created and organized to aid a distinct type of client. As discussed in the previous chapter, The HELPING CENTER is centered on the model of offering aid to a person who needs help with resettlement and basic integration. Their model, on a surface level, lacks a personal relationship with their participants and follows a help and release ideology; offering courses in language and mental health to promote the livelihood of the clients but not steps beyond this initial start. My experience at the HELPING CENTER showed how longstanding the support for this population actually was by allowing me to interview a client who had been residing in the United States for over a decade. This client had already received her permanent residency but was still receiving some form of assistance from the HELPING CENTER.

The organizations at which I was able to observe and participate offered care to clients that did not fit the common mold of what a client should be. Not all of their clients were new to the Boston area. Not all of their clients were unable to speak English. Not all of their clients required assistance with housing or food. Not all of their clients required mental health counseling or services. The refugees and asylum-seekers that became the clientele of these organizations were unique and required varying services, and to the best of their ability, the HELPING CENTER, Ministry for Refugees, and The Place, rose to serve the population.

Healthcare Needs and Understanding

I smile softly at the middle-aged woman sitting to the side of the desk in the small room we occupy. The overhead light glows brightly then dim again, and the soft hum lulls me into a misguided sense of tranquility as we continue to make small talk about the weather and the difficulty of navigating the large New England Safety net hospital we are currently sitting in. She seems to be looking through me as I go through my list of endless questions. “Are you interested in this? Would you like that? Do you have this? How can I help you with that?” She does not look uncomfortable as I ask questions about family, friends, past experiences, suicide or even sexual interest. Instead she keeps her gaze steady seemingly transfixed on something located on the wall over my right shoulder. She drops her gaze only once when discussing those she left behind, and even then it was only for a moment. “I want to see a dentist,” she says with finality in her voice. “Of course! I will let the social worker know” I say, as I internally struggle with the woman’s desire to see a dentist over seeing a primary care doctor, or a mental health specialist, both of whom may help with getting an affidavit that aids her in court while she is seeking asylum. (Field notes, December 2015)

In the case of this client, her needs were acute: she needed to see a dentist to alleviate the pain she was experiencing. This need was greater and more important than seeing a physician who might be able to help with her affidavit for her asylum case. This is not to say that these services were not a priority for her, as simply showing up to an

intake appointment at the Place allows the client to be in contact with a variety of services and specialists who will be able to aid her in her journey for asylum.

The prioritizing of a dental visit may allude to this overall understanding of the Place as an organization that can offer referral to other medical centers or medical providers within the New England area. Her use of the Place and my immediate balking also introduces the concept that this client did not fit the picture of what a client should look like in my mind. She did not want to be treated for mental illness, which went against everything that I had read about mental illness in refugees and asylum-seekers especially with the addition of a torture history (Ater 1998, Lipson 1993, McGorry, 1995 & Silove, et. al., 1993).

Asha, an elderly refugee from Somalia and client of the HELPING CENTER, spoke about her struggles with adapting to the health care norms of the United States.

“So, they would first, the first attempt when you are sick and you don’t know health providers they would give you home remedies, and sometimes it could be oils, it could be natural things like leaves. If you are constipated they would give you leaves to drink as a tea or oils, oil remedies.” Asha

Asha notes that before she had known about health providers she sought out herbal remedies for her illnesses from people in her community. Asha has changed her health-seeking behaviors since involving herself in this new health world. She goes on to discuss how she enjoys going to the doctor in the United States and has a great trust for the healthcare community here. Her understandings of health and healthcare may have been greatly shaped by her community in Boston. The HELPING CENTER boasts a longstanding special relationship with the Somali community and, although outside of

their distinct goals, they have aided Asha's integration into the biomedical world of Boston.

"If I'm going to see a doctor, it varies. I try to see certain things that I can handle by myself. Like when I get headaches, I try to take water and fluids and things. I can try to relax and try to calm down and take immediately a medication for the headache, something that could work for me at the point. Only when it prolongs itself then I know that it is something else, ya, then you have to seek medical attention" Bill

Bill, a middle-aged man, client of the Place, and asylum seeker from South Eastern Africa, has a certain understanding of why headaches occur. It is his understanding that not having enough fluids may lead to pain in his head as well as feeling stressed and not calm. His self-medication and self-treatment points to the control that Bill has over this deviant feeling that he may have in his body. Only after his self-medication and therapy has stopped working does Bill seek the help of a health professional. Either his understanding of what a headache may be or his desire to rid himself of the pain leads him to take action outside of his own hands.

Bill's decision to self-treat with water, then try and relax, then take medicine and finally, if all else fails, to journey to a physician is considered to be his hierarchy of resort. His hierarchy aligns with a common biomedical understanding of a headache. The National Institute of Neurological Disorders and Stroke states,

"Drug therapy, biofeedback training, stress reduction, and elimination of certain foods from the diet are the most common methods of preventing and controlling

migraine and other vascular headaches” (NINDS Headache Information Page 2016).

Working within Bill’s understanding of a headache allows the Place to offer ample support in different ways. They offer a course where clients are invited to come and learn about common healthcare norms in the United States. This “WellBeing” course is a way to integrate the clients into a biomedical ideology and train of thought that is found in the United States. Bill, a student in this class, used the tools offered by the Place to create a distinct understanding of a biomedical problem.

Wounds

Discussions of different health care needs were also greatly influenced by prior knowledge and understanding. Bill, for example, came to the United States with a health world that paralleled that of the biomedical health world found in the United States.

“Ya too much for me to handle when, times when either it’s a wound or you know you’ve got pains in your body and all that, those are times when you usually need to see a doctor because you may say oo let me take it but you don’t know what it may be.”

His understanding and decision-making skills closely mimic the biomedical health standard found within the United States. For example, WebMD, an online website that, “provides valuable health information, tools for managing your health, and support to

those who seek information” (WebMD, About WebMD, 2005) makes a similar point with respect to wounds:

“While a puncture wound may hurt less, it could potentially be more serious if left untreated.... If the wound does not begin to heal or grows red, warm, and/or inflamed, or the skin around it shows red streaks, seek medical care immediately” (WebMD, Wound Care: Your Essential First Aid Care Guide, 2015).

According to this biomedically instructed website, wound care is something that should be taken care of immediately and if it does not heal then seek medical attention for the wound. Bill offered similar sentiments but this may be largely due to his prior knowledge of what a wound may be.

When WebMD gave advice on how to treat a wound, the article began by stating “Burns are particularly painful, as are many blisters, cuts, and scrapes” (WebMD, Wound Care: Your Essential First Aid Care Guide, 2015). This is a common understanding of what a wound may be in the United States and often why little to no medical attention is sought when a person receives a minor bruise or burn. Bill on the other hand appears to have a completely different interpretation of what a wound may be. As a client of the Place, and therefore a victim or primary or secondary torture, Bill may have faced and encountered much more extreme types of wounds or unknown pain and as such has internally reasoned that these ailments require the oversight of a physician or medical professional.

Bill came to the United States from sub Saharan Africa. This region goes through periods of stability and instability and contributes to large numbers of refugees and asylum-seekers in the Western hemisphere. According to the Boston Center for Refugee Health and Human Rights, Uganda, Cameroon, and the Democratic Republic of Congo

are the top three countries from which they receive clients (BCRHHR, 2015). The UNHCR notes that Somalia also has contributed over 1 million refugees (UNHCR Figures at a Glance, 2015).

Refugees and asylum-seekers are able to claim status in the United States by pointing to persecution due to political affiliation and often sexual orientation. According to Amnesty International, homosexuality is illegal in these African countries: “Algeria, Angola, Botswana, Burundi, Cameroon, Comoros, Egypt, Eritrea, Ethiopia, Gambia, Ghana, Guinea, Kenya, Liberia, Libya, Malawi, Mauritania, Mauritius, Morocco, Namibia, Nigeria, Sao Tome and Principe, Senegal, Seychelles, Sierra Leone, Somalia, South Sudan, Sudan, Swaziland, Tanzania, Togo, Tunisia, Uganda, Zambia, Zimbabwe” (Amnesty International, Mapping anti-gay laws in Africa, 2015). It is also punishable by death in Mauritania, Sudan, Northern Nigeria, Southern Somalia (Amnesty International, Mapping anti-gay laws in Africa, 2015). Along with sexual orientation political violence is a large cause for concern in sub Saharan Africa. Elections are often dangerous; in 2007 Kenya, a “stable democracy”, erupted into violence with over 1000 deaths and 660,000 displaced people (Amnesty International, Kenya: Victims still seeking justice for post-election violence, 2015).

Due to their political affiliation and sexual orientation, refugees and asylum-seekers fleeing from sub-Saharan Africa are often targeted and subjected to primary or secondary torture, before fleeing their homelands.

“Primary torture survivors are individuals who were directly tortured under the definitions set forth in this Guidance. People who were forced to witness the torture of another are also considered primary survivors... Secondary torture survivors are family members or close intimates of the primary survivor” (U.S.

Department of Health and Human Services TORTURE SURVIVORS
PROGRAM (TSP) ELIGIBILITY DETERMINATION GUIDANCE, 2010).

Bill's use of the word wound implicates a completely different level of meaning that medical professionals in the United States may not be fully exposed to. A wound to us may be considered a splinter or a paper cut but a wound means so much more to a person who has been exposed to torture in a region notorious for its human rights violations. His understanding of the word stems from a much deeper understanding of what it means to be injured. Coming to the United States and being exposed to the biomedical world does not change what his understanding of the word, his definition and understanding are firmly ingrained due to past experiences of what it means to be wounded.

While Bill never explicitly attributed his knowledge of wound or wound care to his experiences prior to arriving in the United States, I will argue that his past plays a large role in defining current understandings. That is to say that his understanding of wounds and punctures have been defined by his experiences with or around torture in his home country. Bill's healthworld in his home country was affected by his persecution or the persecution of those around him. His new healthworld, while not directly affected by these experiences, is shaped and molded by the collision of past and present, of persecution and now the political identity constructed by persecution.

The Place offers a setting where Bill's understanding of a what a wound is can be discussed and contextualized. With a deeper understanding of Bill's background, providers at the Place offer a safe space that can allow for discussion of wounds and, with its location inside of a hospital, the treatment of wounds. While outside of the expressed

scope of care, the Place utilizes resources and people to create an all-encompassing type of care for their clients.

Illness in the United States

When Bill first arrived in the United States he fell ill, he had a violent fever, a cough, and a stomach bug. When Bill discussed his ailments with his community, they diagnosed and “treated” him. The community had concluded that he had the flu, a common sickness in the United States but a new frontier for Bill.

“I felt like (it) pulled my heart and all that ya. Fever and all that so I think depending because it was actually my first time I got to know ... For me, it was like a new sickness to be exposed to... and actually they say that there are those kind of like that flu that you don’t need to see a doctor here, you first leave it, it goes away by itself. I thought ah I need to go see a doctor and they say it goes by itself you just need to keep taking fluids and uh all that.”

The steps he took to seek care show his understanding of health and healthcare in the United States. When his symptoms first began, Bill took specific note of where they were causing discomfort, allowing him to conclude that he had never experienced this illness before. When he did not know the cause of his fever and stomach pain, he spoke to his community, hoping to gain some insight. The action of reaching out to the community before involving a physician points to an adaptation that occurred once he

arrived in the country. He has come to rely on the advice of his community, listening to their advice on not only how to treat the flu, but also the diagnosis of the flu as a whole.

When talking to Susan she mentioned cancer as a disease that caused her a great deal of anxiety.

“I am concerned about cancer... (Do you see a lot of people suffering from cancer?) I hear a lot”

Cancer is an illness that many people in the world fear. In 2012 alone over 8 million people worldwide lost their lives to this devastating disease.

“In 2016, an estimated 1,685,210 new cases of cancer will be diagnosed in the United States and 595,690 people will die from the disease” (National Cancer Institute, Cancer Statistics, 2016).

According to the CDC, cancer is also listed as one of the top ten causes of death in the United States just below heart disease (CDC, Leading Causes of Death, 2015). Cancer is a huge health concern in the United States and as such it garners a great deal of attention in the biomedical realm. That is not to say that cancer does not exist around the world. According to cancerindex.org, over 20,000 are diagnosed with cancer a year in Uganda and about as many die a year from the sickness. Cancer is not a monster simply rearing its ugly head in the United States but, upon arriving her arrival, Susan has seen how dangerous this illness can be and deemed it a health priority and concern. An analysis of cancer in the Canadian and United States’ media brings light to Susan’s new concern surrounding cancer.

“(C)ancer is, as all diseases are, recognized and experienced within a social and cultural context” (Clarke et, al 2006, 2591-2600).

The illness changes shape as it leaves one cultural context and enters the next. Leaving a region of the world where HIV, tuberculosis and violence are among the most common

causes of death, and entering a country where the primary cause of death is heart disease, a large shift in health priorities is bound to arise (Rao C et al., editors. *Disease and Mortality in Sub-Saharan Africa*. 2006. Chapter 5). Along with shift of priorities, there is a shift in public health concerns which is in turn expressed in the media through commercials, ads, and funding. The researchers found three major themes in the media's relationship with cancer.

“(1) the exacerbation of fear, in many ways, and at all ‘stages’ from prevention to early detection, treatment and beyond; (2) contradictions, confusion and uncertainty in regards to diagnosis, prognoses and treatments; and (3) the frequent deployment of battle metaphors” (Clarke et, al 2006, 2591-2600).

Susan's fear of the illness may be largely due to her new exposure to media reports portraying cancer in such a disconcerting light.

Navigation

Macy is back again today, asking me to get her the meds that she got from the “Place” last time. “I came here and then someone took me somewhere else and then I got the medications.” I saw her three weeks ago and helped to set up an appointment with the Family Medicine Department in the Hospital. I also walked her down to the Emergency Department (ED) and helped her get her medications that same day. The nurse at the check in for the ED sternly told me that she would not be able to get her medications through the ED after the third visit. “If she was a client of ours or a patient of the hospital she would need to get her medications through the primary care physician

so I made sure that we set her up with an appointment to see a PCP hoping that she would be able to get her medicine seamlessly.”

Apparently, Macy didn't make her appointment and now she is out of her medication. “I need my meds,” she tells me again, as I sit with her in the waiting room trying to figure out the next steps to help her. I don't want to go back to the emergency department I don't want to anger the ED staff again. Nobody really knows what to do... I feel bad bringing her back to the ED. I'm swamped with paperwork and am the only navigator here this afternoon. The new social work intern, Jessica, ends up helping her. When she returned from helping the woman, Jessica tells me that she was able to set her up with another primary care appointment and that the woman was able to get her medication today. I hope that she keeps the appointment!

(Field notes October 2016)

Sometimes the best way to understand a process is to simply go through it and see what happens. When you find something that works, you stick with it. When you find something that does not work, you change methods and hope that the next steps work out well. In Macy's case, she was able to manipulate the system and make it work in her favor. The “Place” acted as her starting point, a place where she felt comfortable and knew that she would be able to receive help and care. Entering a large unknown setting is intimidating and uncomfortable, especially a setting such as a hospital, where people are constantly running around to get to and from appointments. The “Place” acted as a safe space where she could sit and relax, Macy knew that somebody would be able to help her if she just sat and waited in the waiting room.

The biomedical health care system that is set up in the United States is not easy to navigate. Determining steps to take when one gets sick relies heavily on a refugee or asylum-seekers understanding of how the health care system works. If a person has insurance and a primary care physician, the next logical step might be to go see the physician in order to be diagnosed and subsequently cured of the ailment. If one has health insurance but does not have a primary care physician then they may suffer for a great deal longer before reaching out to a physician. In the case of the women noted in the field notes above, she had insurance but did not understand how to navigate the subsequent health care maze.

The creation of this woman's health care pattern was largely a result of her primary visit to the hospital as a "walk-in". She came with knowledge that a clinic existed within the hospital that catered to the needs of refugees and asylum-seekers. Once arrived, any available staff (except for the navigators) can be utilized to help determine if a person is eligible for the services of the clinic by determining if the person is a primary or secondary victim of torture. On the day that this woman first arrived, she was seen by one of the staff members and then passed to a navigator in order to help apply for state health insurance.

After this initial contact with the "Place", Macy identified it as a place where she could go when she needed help with any and all medical needs so when she returned within the month, Macy expected to receive her medications. With the help of various departments within the hospital, Macy's expectations were met and we were able to help provide her with a way to receive her medications. Aligning with the goals of the

“Place”, we were also able to help set her up with a primary care physician so Macy will be able to get her medications filled on a regular basis.

The journey that this client took to fix her problem aligned with her experiences of being a patient at the hospital. If Macy went to the “Place” and sat in the waiting room, she would eventually be led around the hospital and be able to receive the medicine that she needed. Her solutions did not align with the solution that the “Place” had. After her first visit to the “Place” after her initial “walk-in” visit the priority was to get her the medications that she needed as well as setting her up with a primary care physician who would be able to help her get her medicine and also act as guide to any health-related questions that she may have. Macy’s journey to receive her medication may have not been the common route in her home country. For example, in a study looking at the access to and use of medications in Uganda, it was found that a majority of the medications were acquired through a private pharmacy or drug seller. The next most common occurrence was acquiring medications through a public health care facility (Ministry of Health, *ACCESS TO AND USE OF MEDICINES BY HOUSEHOLDS IN UGANDA*, 2008, 18).

Conclusion

The stories written above provide a portrait of the diverse clientele that each organization may encounter and assist. Within the biopolitical realms each organization occupies, the desires and needs fluctuate, growing with a client’s understanding of their own health and the health care that is offered in the United States. They develop new

hierarchies of resort, as seen by Asha's desire to seek biomedical care from a physician instead of herbal supplements when faced with constipation. They meld their understandings with that of the predominate health world as seen with Bill's understanding of a wound and the way that he addresses the ailment within a medical setting.

Navigation of a new health care setting and health world ultimately favors those who follow the rules, but to fully understand the way a system works, one must be embedded. The HELPING CENTER, Ministry for Refugees and the Place offer settings that allow refugees and asylum-seekers to discover these boundaries, to utilize the expertise of health care experts to receive "proper" care and to develop individual ways of thinking of their own health. This safe space of sorts is a way that these organizations are able to resist the rigid moral economy, they extend the roles to make people deserving of specific services. This stretching of services makes a moral statement that these organizations value people beyond a defined category. Pushing the boundaries of this care lends a hand to refugees and asylum-seekers that are beyond the official scope, living on the edges of a particular healthcare landscape.

The Fringes

He walks in with a huge smile on his face. “I got work authorization!” Eugene says to me as I greet him in the waiting room. I offer him tea as he takes a seat to wait to see his physician. After meeting with the doctor, he knocks on the patient navigator door, “I would like a Charlie Card if you have any left for the month.” “They didn’t tell you?” I ask. I explained to him that the “Place” does not offer Charlie Cards to anyone who is able to work legally, so Eugene isn’t able to receive a card for his appointment. Two weeks later Eugene missed his next appointment, and when I call him to see if he would like to reschedule, he tells me he doesn’t have enough money to pay for transportation to the “Place” anymore. His mental health appointments lose priority as the realities of being on the fringes—not quite an asylee or refugee -- become visible. Unable to receive the benefits those identities encompass, but being defined by the parameters of those identities, Eugene prioritizes his life in the fringes.

Eugene has fallen into the “holes” of care at the Place. He has work authorization, so it is assumed that he will be able to make enough money to make it to his appointments. Similarly, when Eugene is able to get a job he will likely miss even more appointments due to the overlapping schedules. In Eugene’s case, he had to make a decision based on the structures that surrounded him. He only had a certain amount of money, he knew that he would have to spend money on transportation to and from the Place, and due to funding policies, the Place was unable to offer more aid due to Eugene’s possible earning potential.

Asylum-seekers in the greater Boston area are constantly on the fringes of care and services. A majority of their livelihood is reliant on certain expectations, obtaining a political identity, proving their deservingness by fitting the mold of what a refugee or asylum-seeker is supposed to look like. The benefits of the terms refugee and asylum-seeker collide with the disadvantages in seemingly odd ways as shown through Eugene's tale. The HELPING CENTER, the Ministry for Refugee's, and the Place all offer support in varying ways to those people who find themselves located on the fringe.

The defining factors of both a refugee and asylum-seeker require that they both have left the physical borders of their home country and have a well-founded fear of persecution if they were to return. While a person may have fled their country, and demonstrated a well-founded fear of persecution or death, it is up to the government in which they are seeking shelter to determine if they will be politically identified as a refugee or asylum-seeker. While the United Nations High Commission for Refugees (UNHCR) may identify a person as a refugee or asylum-seeker as such, it is ultimately the receiving country's decision to uphold and give the benefits that the political identities entrust.

Finding Work

There is often a certain stigma associated with new immigrants; some people claim that they are taking the jobs of natural born citizens, others claim that they are "lazy" and simply living off of government handouts that taxpayers provide.

Refugees receive work authorization upon arrival to the United States. This does not automatically mean that those with refugee status will be able to secure employment in the field in which they were working in their home countries. For example, if a person was a physician in their home country, they may be forced to jump through many hoops before being able to practice in the United States.

“(A) doctor is only allowed to practice in the U.S. once he has obtained a license in the state in which he intends to work. The person must acquire a visa, pass the first two steps of the United States Medical-Licensing Exam (USMLE), then become certified by the Education Commission for Foreign Medical Graduates (ECFMG), get into an accredited U.S. or Canadian residency program, and finally, go back and pass step three of the USMLE. Each of these steps could take multiple years, repelling doctors who are already able to practice in the country in which they were trained,” (Sopher, 2014).

These steps do more than cost precious time; they also point to a lack of trust for outside education systems. By forcing people to redo years of labor to get to the point that they are recognized in their profession can demean the education system as a whole and create a new stressor on top of acclimating to a new country.

Work Authorization

While the path to an American based normality may seem difficult for refugees, asylum-seekers are burdened with a worse fate. As an asylum-seeker, one is not allowed to work upon entering the United States. If the asylum claim has been processed and granted by the U.S. Citizenship and Immigration Service (USCIS), the agency will file for your work authorization. If an immigration judge has granted you asylum, then you will receive instructions on how to file for work authorization in the mail by the USCIS

and will either have to go to a USCIS office to finish the procedure or mail in the application (USCIS: Asylees and Refugees, 2016).

The main problem with this system is that asylum claims can take years to process. Asylum-seekers are able to file for a work authorization permit 150 days after they have sent in their initial asylum-seeking claim permitting that there has been no decision on the asylum-seeking claim. Technically one is supposed to wait 180 days after applying for asylum status and receiving no decision to file for work authorization with the USCIS, but they allow you to apply early as long as it is known that you will not receive status until at least 180 days after the initial filing (USCIS: Asylees and Refugees, 2016).

“As identified in Human Rights Watch Report, *At Least Let them Work: The Denial of Work Authorization & Assistance for Asylum Seekers in the U.S.*, ‘Asylum seekers often wait much longer than 180 days before receiving work authorization. Sometimes, asylum seekers wait months or years before they either win their asylum case or their clock starts up again. In extreme cases, applicants have been without work authorization for nearly a decade while their cases are adjudicated in various stages of appeals.’ In 2012, a group of asylum seekers supported by pro bono legal aid providers brought a class action lawsuit against the U.S. immigration department challenging the practice of allowing immigration judges to stop the asylum clock, and thus deny them the ability to obtain permission to work.” (Wirth et. al 2014, 37)

The *Global Refugee Work Rights Report* above notes the limitations and exploitative factors associated with work authorization attempts.

While doing participant observation at the PLACE, I encountered a young Syrian woman who had been in the United States for almost five years. She applied multiple times for work authorization and was denied every time. This young woman did not know why she had been denied but the fact that she had been after being in the United

States for almost half a decade is telling of the system surrounding work authorization.

By the point that I was introduced to her, she was extremely disheartened. A Human

Rights Watch report on work authorization in the United States:

“(T)he hardships asylum seekers face in four major areas as a consequence of being denied work authorization: psychological harm and interference with the ability to heal after torture and persecution; economic hardships and vulnerability to further victimization; the physical and health-related hardships created by an inability to provide for oneself; and difficulties with access to legal counsel in pursuit of asylum claims and work authorization.” (“Atleast Let Them Work”, HRW 2013)

Not only does work authorization limit the economic access that impedes the basic livelihood of asylum-seekers, it also has extremely damaging health effects.

The Ministry for Refugees is one of the few organizations in the Boston area that offers housing to asylum-seekers through their cluster systems. One of the main factors in receiving housing aid and keeping the help is that the asylum-seeker must not be working without work authorization, if they are found to be working illegally and under the table, they are automatically kicked out of the cluster. This is not done with malicious intent but instead a result of the way that the organization is governed by a larger biopolitical system. The government says that you need work authorization to legally work and in order for the Ministry for Refugees to offer aid they must make sure that all of their clients are following the rules and regulations that are placed on them by the larger governmental powers.

Curfew

“I have to go soon” I hear as I glance up at the middle-aged woman entering the Patient Navigator room. “I have to leave now” she continues looking increasingly

distressed as she looks around the room. “Okay, well the food pantry doesn’t open from its lunch break for another hour do you-” , “I have to go now or she will lock me out of the house and I will have nowhere to stay for the night” she cuts me off. “Okay” I reply, I ask her to stay until I tell her provider that she has to leave and why she needs to leave so urgently”

Relying on another person’s helpfulness or compassion to survive is something that is often a reality for asylum-seekers. Housing in Boston is difficult to come by and without a job it is increasingly difficult to find somewhere to stay safely for what may end up being an extended period of time. While working at the Place a common theme that emerged was clients missing appointments or showing up late to appointments due to demands of others around them. They had to leave early because the person they were staying with was leaving for work and wanted to lock the house before they left for work. A friend who was supposed to give them a ride had something else come up so a patient is left without a form of transportation. A client wants to see the doctor next week but can’t create a schedule that works with both the doctor and their friend who is driving them.

It is beyond the scope of care that the Place can offer to provide housing for client’s who are experiencing bad living situations. The best option that providers can offer is help getting into homeless shelters in the surrounding areas. In these cases, providers often have to work their schedules to the best of their ability to see clients while also offering emotional support for the effects of said living situation. There are strict

rules associated with the hospital that prevent the staff of the Place from offering care beyond the clinical setting, a source of frustration for many of the providers.

As I help the young woman gather her things from the waiting room I can't help but think of my pullout couch that I could offer her for the night if she was ultimately locked out of her house. It's cold outside and she only has an hour to get home if her roommates threat is real. The hospital has strict rules against any contact with clients outside of the hospital setting and equally concrete guidelines that deny the sharing of any personal information with clients so I quickly push that thought to the back of my head as I help her gather the rest of her things.

Conclusion

What would you do if faced with this dilemma? What can you do? I spoke to an asylum-seeker from Uganda who told me that in order to get the help that she needed, she had to “Suck up her pride.”

An accomplished woman, Mary had multiple degrees from universities not only in Africa, but Europe and Asia as well. She told me stories of her first time in Russia where she saw snow fall for the first time. She spoke eloquently as we discussed her passion for languages and for experiencing new cultures. She told me that one of the most difficult things she has done is come to the Center and discuss her problems with women who could have been her daughter. The ultimate dilemma lies in store for asylum-seekers entering the United States, do you work and risk detention or even deportation? Or do

you “Suck up your pride” and take the charity from friends and organizations for an unknown period of time?

Refugees and asylum-seekers complex presence that makes it difficult for governments and aid workers to fully offer aid in the most direct and appropriate manner. When fleeing a country, having a way to gain income and take care of oneself is not always the first priority. Once a person is residing within a new country, they must face the task of creating a new life for themselves. The government and other aid groups must figure out a way to allow the population to create a life for themselves while still offering aid to support them along the way. Creating a way for refugees and asylum-seekers to learn how to navigate their new homes will allow them to create a way of life that themselves have deemed appropriate and complies with cultural norms of their surrounding homes.

The system that refugee and asylum-seeker aid organizations, such as the Place and Ministry for Refugees, operates under does not necessarily work. We see the broken nature in the fringes where many of the clients reside. An asylum-seeker may wait years before gaining their work authorization and while they wait they are expected to not work at all. During this time, they are denied the benefits of a job; financially, emotionally, and physically. If they are found to be working under the table they may be deported or have any other assistance, such as housing, stripped. If they choose to work under the table, asylum-seekers may be taken advantage of by employers. Employers know how much they need the money and how scared this population is of being found in such a precarious situation.

Lack of funds for this population can force them into unstable living environments that, while well meaning, deny sorts of self-sufficiency and may compound emotional distress by feeling as if they are burdening those around them. “Sucking up your pride” as Mary discussed can also make one feel helpless, this is amplified by the already fickle political status and livelihood of many asylum-seekers in the greater Boston area.

The organizations work hard to offer the most complete and holistic care that they are able. Overhanging structures such as government funding and laws work to pushback against these organizations and help to create the fringes where many of the refugee and asylum-seeking population have found themselves.

Conclusion

Aid organizations face the challenge of simultaneously filling the role of a biopolitical power and acting as a tool to push the boundaries created by the overlying biopolitical powers. Organizations such as Ministry for Refugees, the Place and the HELPING CENTER help refugees and asylum-seekers by offering specific services. Each service is given and received with the intent of maintaining a certain quality of life for the refugees and asylum-seekers receiving the care. Organizations offer services that have been deemed important: mental health care, community services, English classes and housing services. The agencies ultimately determine who is worthy of each service and how often they may receive them. The organizations maintain control over the bodies of the refugees and asylum-seeking population that they serve.

Health Literacy

Health literacy is a common point of reference for analyzing both health knowledge and reactions to illness by the biomedical community. As stated above, health literacy is

“(T)he degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions.”(CDC 2015).

This definition claims that there is a specific health decision that is appropriate for each problem, one answer for one question. Through my research at the Place, Ministry for Refugees and the Helping Center, I have found that these organizations strive to create multiple answers for one question. Each organization works to help maintain the health

and livelihoods of their refugee and asylum-seeker clients. In their maintenance, they do not force a particular ideology, allowing their clients to find different routes to care. As seen in the case of Bill, his health literacy did not exactly match that of his providers when it came to identifying a wound but the Place created a space where his understanding and reactions to a wound were not only treated but also embraced.

Healthworlds

To maintain health and livelihood of refugees and asylum-seekers, the Ministry for Refugees, the Place, and the Helping Center worked within the healthworlds of their clients in able to give the most sufficient and holistic care that they were able to offer. Healthworlds, as stated before, is a term that is used to identify the complex web that is created when discussing health. It takes into account religion, social structure, relationships and other aspects that are used to make health based decisions.

Through my research, I observed how each client had their own healthworld, their own reasons for making complex decisions, their own beliefs and concerns that shaped and nurtured their health seeking experience. While the organizations from which they were receiving, care did offer new insights to health and livelihood in the United States, they also created room for their clients healthworlds to grow. They introduced knowledge of how to create doctor's appointments or to get food, they offered courses in being "healthy" in the United States, and offered support every step of the way. They did not force their clients to completely abandon their original health seeking behaviors but instead

created safe spaces for which their healthworlds could not only be utilized to receive care, but also where their healthworlds could grow.

Ethnomedicine

Fabrega's concept of ethnomedicine or,

“The study of medical institutions and of the way human groups handle disease and illness in light of their cultural perspective” (Fabrega, 1977: 201) is extremely useful to analyze the way that clients at each organization formed their health seeking behavior. By using their own culturally formed understanding of health and healthcare the clients used ethnomedicine to create their healthworlds and as such their health seeking behaviors. Similar to healthworlds, the Ministry for Refugees, the Place, and the Helping Center, all offered ways that clients could still maintain services even if their ethnomedical ideals did not align with the ethnomedical ideals of the staff or the organizations themselves. Health and healthcare are both deeply ingrained within a person. Each organization worked to still offer services to clients. For example, the Place, even when faced with a client who did not want mental health services even after a great deal of trauma, did not force clients to change their understanding of mental health services. They worked with the clients to offer the services that they desired, acting as a support regardless of their opinions of the clients. In the cases of healthcare providers, it is difficult to not be able to offer services to those that they deem need it, but these organizations strove to respect their clients ethnomedical ideals and create environments

where their health seeking behaviors could thrive and allow them to receive the most holistic care possible.

Pushing Boundaries

The organizations also push the boundaries by allowing their services to fit a specific situation, the actual client, instead of simply offering aid in one linear way. Providers and staff at all three organizations worked to actively move around the biopolitical guidelines that helped to form the basis of their organization. Biopower does not take into account that workers bound by it find a way to build around and through the rigid structures. The overarching biopower is limited by the local moral economy found within these organizations. As Sarah Willen stated,

“Within any given local moral economy, different stakeholders and groups of stakeholders reckon such matters as inclusion and exclusion, deservingness and undeservingness, in markedly different ways.” (Willen 2015:72)

The organizations have deemed their clients, refugees and asylum-seekers from around the world, to be inherently deserving of care. Each organization has a unique origin story that pays homage to a distinct history that creates this deservingness. Ministry for Refugees was formed based on the moral economy surrounding the idea that detained persons deserve to be heard and allowed spiritual guidance. The Helping Place’s foundation is based on the need for a sense of community for Somali women and children. The Place is founded on the idea that refugees and asylum-seekers are deserving

of mental health and legal care. Beyond a shared organizational history, staff have their own reasons; memories, expectations, and values, that constitute their moral economy. Some are refugees themselves, others have felt drawn to helping this population due to their families or friends. This form of moral economy, a moral economy based and built upon the inherent deservingness of refugees and asylum-seekers, breaks the confines that are placed by the overarching biopower and allow for these organizations holistic care of their cliental.

Macy is a prime example of an organization helping and creating a pathway outside of the rules and regulations that it has founded. When Macy came to the Place for her medication instead of going to her primary care appointment, she was going against the norm and the way that we were taught to allow her to receive her medication. Instead of simply making her reschedule an appointment and sending her on her way, the Place allowed me to take Macy down to the emergency department to get her medication.

Ideal Clients

Each organization has an ideal client, the refugee or asylum-seeker that they had in mind while developing the mission statement. The reality of the clients that each organization caters to shows how fluid the population is as a whole. Clients prioritize dentists over mental health providers, have different preferences for health seeking activities and have different understandings of the things that make life efficient in the

United States. Each client is different and all three organizations offer services in a way that is customized to individuals.

Care

What does it mean for these organizations when they say they are offering care? The care that they are offering shows that health care does not equate to medical care. While providing for the basic health of the individuals requiring services, these organizations also go further to offer a holistic approach to this population. Beyond this generalized holistic healthcare model, these organizations offer individualized care, a concept that directly contrasts biopower, and more specifically anonymous care.

Anonymous care is a term that Lisa Stevenson used in her ethnography, *Life Beside Itself*, an ethnography that focuses on the suicide epidemic within the Inuit population of Canada. She focused her exploration into the modes that the Canadian government were taking to keep the Inuit population alive. She argues that while the government offers services, they do so without regard to the individuals whom they aim to maintain. The Inuit people have become numbers to keep alive, and the government has taken control of their lives by forcing them to seek services, such as the suicide hotline. Stevenson argues that this form of care, while seeking to maintain and proliferate life, harms those it aims to help. Anonymous care, through its innate standardization of care and of life, becomes the means of providing benefits on the basis that simply living is enough (Stevenson, 2014). The approach of the care through being alive is a common

thread but the through organizations that I worked with, I have seen how the concept of anonymous care dissipate and individualized and customized care emerges to help maintain the lives of the refugees and asylum-seekers in the greater Boston area beyond simply keeping them alive.

While the Ministry for Refugees, the Place, and the HELPING CENTER all offered specialized services, they were able to adopt an interlaying web that connected in various ways. Referrals could be sent from each organization to any of the others and clients were able to navigate through the agencies to find a way to create the best plan for themselves. The ability of each organization to be fluid within a larger and more rigid set of guidelines allowed for the most holistic form of care for the refugees and asylum-seekers in the greater Boston area.

Disruption of Biopower

Biopower in itself suggests that while organizations offer aid and resources to people, intrinsically they enforce discipline, surveillance and a certain degree of social control. Discipline in the way that organizations force a regiment in order to receive care, a person must go to the scheduled medical appointment to receive medication. Surveillance in the way that a person may be monitored, that if they are observed working without work authorization, the care will end. Organizations offer social control by creating communities that are monitored and under the realm of their umbrella. If a

person is unable to follow the rules, they are rejected from the social community that has been created.

This understanding of biopower does not match with everyday discourse that I observed while at Ministry for Refugees, the Helping Center, or the PLACE. These groups strove to be adaptive to their clients, to allow for an ebb and flow within the walls of biopower based establishments. While still enforcing rules, these organizations were able to offer care at the local and individual level. These groups worked within the rules to create a form of aid that went beyond simply keeping a person alive. The staff and clients of these organizations were able create and maintain a system that allows refugees and asylum-seekers to experience the care that they deem fit.

Limitations

While I had a great deal of accessibility to the population through my participant observation, my interview sample size was not large. With only four direct semi-structured interviews, I was unable to get direct answers to some of my research questions. My small sample size was limited by a variety of factors. Refugees and asylum-seekers are considered a vulnerable population. They have been persecuted and subjected to horrors prior to their arrival in the United States. The vulnerability of the population made it extremely difficult to find a group that would allow a graduate student to access and interview their clients. When I was able to gain access to a site, scheduling interviews became difficult. My first interview ended up arriving almost an hour late and

my next had to cancel and reschedule two times before I lost contact. At the Place, scheduling also proved difficult as I was only allowed to interview clients before or after their appointments. While the timing was tight, it was confounded by the time limitations that clients had before or after their appointments. The bus schedules along with rides that they got from friends made their free time extremely limited and scheduling interviews provided to be difficult.

Recommendations

Aid organizations that center on the care of refugees and asylum-seekers stateside should follow models of healthcare that encompass the stated needs of their clients. By creating a biopolitical structure that factors in the direct needs and struggles of refugees and asylum-seekers, the organizations would be allowed to grow in ways that would directly bring about change instead of forcing organizations to push boundaries. Those clients that are living on the boundaries of care and services should also be given a voice as their lives and livelihood are just as deserving of care as the refugees and asylum-seekers situated safely within the reaches of organization and self-sustained care. Furthermore, we must acknowledge that these people are not just broken and suffering, they are resilient people who are able to make rational decisions to positively affect their lives and livelihood.

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