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BOSTON UNIVERSITY

SCHOOL OF MEDICINE

Thesis

MENTAL & MUSLIM

THE IMPACT OF STIGMAS ON COMMUNITIES

by

KANWAL HAQ

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Master of Science

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DEDICATION

"The idea that some lives matter less is the root of all that is wrong with the world"

-Paul Farmer

I dedicate this thesis to my participants
and to all whom have lost their lives due to struggles with mental illness.

ACKNOWLEDGMENTS

To my program director, Dr. Linda Barnes, my past and present mentors,
and the mental health professionals who have helped me for over a decade-
I am forever indebted to you for your infinite guidance and unwavering support.

To my family and friends- I am here because of your love.

MUSLIM & MENTAL:

THE IMPACT OF STIGMAS ON A COMMUNITY

KANWAL HAQ

ABSTRACT

Since September 11, 2001 there has been much commotion regarding the Muslim-American community. Constituting one percent of the U.S population, Muslim-Americans represent a multitude of ethnicities, socioeconomic classes, beliefs, preferences, and behaviors, occupying a multitude of worldviews--those arising from their various religious and cultural heritages and those innate to their American roots. Muslim-Americans' unique hyphenated-identities, imbued with historical and political significance in the post-9/11 era, makes them vital to understanding the current landscape of minority mental health. While existing literature examines Muslim-Americans perceptions of mental health, focused exploration of Muslim-Americans lived experiences with mental health has been limited. This study investigates Muslim-Americans perceptions of mental health using standard ethnographic methods: in-depth and open-ended interviews, and immersion as participant observer in the research population at a local Islamic center and through community events. The findings suggest that: 1) Muslim-Americans' interstitial identity, compounded by socio-political and religious-cultural frameworks, shapes their perceptions of and attitudes towards mental health and 2) mainstream American narratives of mental health care and support do not adequately accommodate varying approaches to personhood and well-being.

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CHAPTER 1: AN INTRODUCTION

"Hope has two beautiful daughters; their names are Anger and Courage. Anger at the way things are, and Courage to see that they do not remain as they are."

-Saint Augustine

Friday
7:06PM
January 27th, 2017

It's 7 PM on a Friday evening, the sun has already set two and a half hours ago because that's the only way to experience a Boston winter. Tired and "hangry", I attempt to sit patiently in my chair until my peers join. Every Wednesday night, in a classroom just to the right of the *musalla*, the prayer space, women from the mosque gather for a weekly support group. Our group is supposed to start at 7PM, but like many other Muslim gatherings, everyone runs on something we call "Muslim Standard Time", i.e. perpetually late.

As the participants slowly start to trickle in, I watch the overwhelmingly boring space between plain beige walls now begin to transform. Some women come dressed in bright and vibrant hijabs wrapped in a myriad of ways, other are adorned in long abayas- dresses which flow from one's neck to ankles, and then there's a handful like me, those who simply show up in blue jeans with their hair unbrushed.

The 12 women in the room are diverse in a plethora of ways- from race to age to profession. There are women in their early 20s to those in their late 60s. Some are students, some are mothers, and some are newly migrated to the USA; by just looking at

us you probably can't find a common thread, except that we are all women, and presumably Muslim.

Normally when the room is finally full, it's abuzz with laughs and loud chitter-chatter until our facilitator asks us to quiet down so the session can begin. Today, however, the room is quiet.

No one is speaking, and the solemnness of the room is suffocating. I feel like I can't breathe, and I am trying not to cry. I look over and see one woman hunched over and sobbing, while another puts her arms around her and tries to console her.

Today the Muslim ban was signed. President Donald Trump gave an Executive Order banning foreigners from seven predominantly Muslim countries from visiting the United States, and he suspended entry to the country for all Syrian refugees indefinitely. The woman who is crying is from Syria. Her mother and children are still in Syria.

As it hits me, what all of this means, now the tears start pouring, burning hot and uncontrollably, down my own face.

***

Today, just 72 years after the largest Nazi concentration camp was liberated, President Donald Trump takes us back to the old, deathly mistakes of history. On International Holocaust Remembrance Day, Donald Trump has signed an executive order to ban Muslims from the United States. This executive order validates the faces of my 6th grade classmates after 9/11. That I do not belong. These executive orders turn what should always have been "illegal", discrimination based on color and religion, into

something much more treacherous than legal discrimination. These executive orders have turned people's fear and lack of information into moral justification for the process of dehumanization.

Today, all of those scrunched up noses, all of those accusatory looks, are piercing into me. All of those individuals whom I have constantly engaged, all of the communities other than my own into which I have poured my heart and soul, all of those places in which I have tried my best to dispel fear and frustration—it seems to all have been wiped away. My fears, the ones that people constantly called "overrated", my fears that are often overlooked or labeled simply as irrational, my fears that no matter how hard I worked to be a good, upright, moral citizen, at the end of the day- people would still only see what they can see, only what they want to see. I am terrified. Because today, how am I to advocate for the mentally ill? How am I to bring attention to the emotionally distressed? How am I to do this when the government has made it legal to strip someone of my identity of their humanity? My body is aching, and I am worn. Completely worn. Exhausted and ripping at the seams.

Therefore, as you read this, I hope you try to understand; that I began this work so we could keep from repeating the same patterns and mistakes. So that we could finally gain some sort of insight into the difficult experiences others go through behind closed doors. So that we could learn to acknowledge and understand the different types of pain and suffering- and move to a place beyond just those physical extremities. To create a place where we could better engage, educate, and relate. Build a world that welcomes empathy.

Nevertheless, today these orders were signed, and all I could do was continue sitting in a hard, cold chair, continue to sit through a class with my peers. As I sat there, one of only a few colored bodies in the room, I listened to the laughter, the calm demeanor of the room. Many of these folks did not have to worry about the immediate destruction these executive orders would bring. Unlike some of their Muslim peers, many didn't have to worry about being catapulted from their studies, sent back without warning. They didn't have to worry about explaining to their loved ones what such a ban would mean. They wouldn't have to listen to their mothers crying, or watch their families be torn apart. They could be sad and frustrated and hurt and worried, of course, but their bodies provide a valid shield of safety, one that can never be extended to include my own.

Their reality and mine are not the same.

Enough.

After thirteen years of many personal experiences of pain, I finally decided enough was enough. All of the turmoil I had endured pushed me towards working on something bigger than myself. In the winter of 2014, I decided to find a way to give voice to some of the most vulnerable amongst us: those who are children of immigrants, who are people of color, and those who are living with mental illness. Every milliliter of blood in my body pushed me to unearth the truths of those suffering, those who had never been given a chance to speak up, and even when they tried, their voices were constantly shut down.

As I began my research, I was laden with a thousand anxieties. Would I reveal my own stories, the stories that had propelled me to do more, to see more, to learn more? However, those same stories are the ones that we had been taught to keep hidden; those same stories are the ones we are not allowed the luxury or privilege to reveal. Would I share such stories?

Ultimately, I decided I would allow myself and my family the same veiled protection that was offered to my participants. To my participants, I revealed my stories. It was important for me to build rapport, to convey the personal significance this research entailed for me. As you delve into the chapters ahead, you will hear from 10 participants: Laila, Noora, Ibrahim, Raheem, Niyaz, Mustafa, Yasmin, Maria, Laiq, and Bisma. You will hear their stories, learn of the ways in which they learned to define wellbeing, the factors and experiences that shaped their perspectives, and how they have navigated challenges and vulnerabilities associated with revealing information and accessing resources and care related to wellbeing. Within the ethnographic data, autoethnography is also entwined and with all these stories together, I hope we can unlock the door and begin addressing mental health needs for those who are suffering.

CHAPTER 2: BACKGROUND- WHAT YOU NEED TO KNOW

"The media's the most powerful entity on earth. They have the power to make the innocent guilty and to make the guilty innocent, and that's power. Because they control the minds of the masses."

-Malcom X

As later chapters delve into the question of how and why Muslim Americans define and utilize resources and services related to mental health- this chapter aims first to provide readers with a brief history of Muslims in America, a historical timeline on mental health in America, and previous research on Muslim-Americans and mental health.

The Muslim-American Community: A Brief History

While the tragedies of 9/11 have introduced the word "Muslim" to most Americans, 2014 Pew studies show that only 38% Americans know a Muslim, despite there being between 3-6 million individuals, comprising 1% of the total US population. While nativism and exclusionary immigration laws of the early 1900s and rise of anti-immigrant sentiments at turn of the 20th century have attempted to erase and limit the history of Muslim-Americans- Muslim Americans have been a part of American history prior to the formation of this country on July 4, 1776. From early explorers, to fighters in the revolutionary war, the social fabric that constitutes the United States has always included Muslim Americans.

This section draws on the works of historians, sociologists, anthropologists, and other researchers to provide a brief overview of key historical concepts and existing literature on the Muslim-American community.

Before delving into the history of Muslims in America, it is important to remember how history is told and *why.* The historian Hayden White asks:

> *"But what kind of meaning is absent or refused?*
>
> *The fortunes of narrative in the history of historical writing give us some insight into this question. Historians do not have to report their truths about the real world in narrative form…..It is this need or impulse to rank events with respect to their significance for the culture or group that is writing its own history that makes a narrative representation of real events possible.*
>
> *It is surely much more "universalistic" simply to record events as they come to notice. And at the minimal level on which the annals unfolds, what gets put into the account is of much greater theoretical importance for the understanding of the nature of narrative than what gets left out. But this does raise the question of the function in this text of the recording of those years in which "nothing happened."*
>
> *For in fact every narrative, however seemingly "full," is constructed on the basis of a set of events which might have been included but were left out; and this is as true of imaginary as it is of realistic narratives. This consideration permits us to ask what kind of notion of reality authorizes construction of a narrative account of reality in which continuity rather than discontinuity governs the articulation of the discourse."*

(White 1980)

Thus, history is often legitimized through a "closed-structured narrative", alluding to the authority behind the text. To work towards an equitable preservation of events and stories, the reader must be aware of *how* they are accessing the historical information, *whose* stories are being told and *who* is telling the story. Dr. White continues:

"Is it possible that their supposed want of objectivity, manifested in their failure to narrativize reality adequately, has nothing to do with the modes of perception which they presuppose but with their failure to represent the moral under the aspect of the aesthetic?

And could we answer that question without giving a narrative account of the history of objectivity itself, an account that would already prejudice the outcome of the story we would tell in favor of the moral in general?

Could we ever narrativize without moralizing?"

As I begin to delve into the discussion of Muslims in America, I ask my readers to keep these sentiments in mind. Certain histories have been repeatedly erased, used strategically as political techniques, oftentimes working towards the continued devaluation and oppression of people of color. And when alternative narratives of history do arise and are put forward for consideration, they are often met with strong backlash and criticism and a certain course of rhetoric takes place. Such has made it difficult to collect information on Muslim American history. The closest of chronologies is an amended compilation by Abdus Sattar Ghazali- based primarily on the 20th century works of: archaeologist and linguist Howard Barraclough "Barry" Fell, anthropologist and historian Ivan van Sertima, art historian and collector Alexander Von Wuthenau, researcher Hisham Zoubeir, and consultant Fareed H. Nu'man. The combined work of these scholars directly represents significant Muslim presence in the early Americas, starting nearly 300 years prior to Christopher Columbus's 1492 "discovery".

Prior to 1776

The 1178 Sung Document, a Chinese document, points to the earliest presence of Muslims in the New World by way of the voyage of Muslim sailors to Mu-Lan-Pi, known today as America (Bleich 2013).

In 1310, a Muslim king, Abu Bakari, of the Malian Empire, began a series of sea voyages to said Mu-Lan-Pi and by 1312, many African Muslims explorers known as Mandinga, originating from Mali and other parts of West Africa began to explore the Gulf of Mexico and the Americas, using the Mississippi River as their access route.

In 1492, the year Columbus sailed the Ocean Blue, was the fall of Al-Andalus, the Muslim rule of Spain, which had lasted for 700 years. The Christian Spanish explorers were previously soldiers who had fought against the Muslim States; and they carried those anti-Islam sentiments with them as they explored the New World (Mroueh 1996).

In 1513 the Ottoman admiral and cartographer Piri Reis completed a world map, one that would come to be known as a map that surpassed any and all existing maps in practicality and artistry; this map included the Americas.

In 1527, over 200 years prior to the Declaration of Independence, the very first Muslim with an intent to settle in America, arrived. His name was Estevanico, known to his community as Stephen the Moor, or more often than not simply by his skin color, as "el negro". Estevanico was raised as a Muslim but in order to "obey" his Spanish master, Pánfilo de Narvaez, and travel to the New World, he "converted to Catholicism", quietly remaining a practicing Muslim throughout his life. Throughout the 18th and 19th centuries, many West Africans would be uprooted from their homes and brought to

America. Nearly a third of these individuals were Muslim; they were designated as Moors and "de-Islamized", creating a fusion of Muslim and Christian beliefs(GhaneaBassiri 2012).

1776-1900s

During the Revolutionary War, from April 19, 1775 – September 3, 1783, Muslims soldiers, notably Yusuf Ben Ali, Bampett Muhamed, Peter Salem fought for American freedom (Curtis IV 2010). In 1807, Yarrow Mamout, an enslaved African Muslim, was set free in Washington DC, and he later became one of the first shareholders of the second chartered bank in America, the Columbia Bank (Austin 1984).

Muslim immigrants who came to America by choice also contributed much to the fabric of American culture. In 1839, the ruler of Oman, Sayyid Sa'id, set sail for America aboard his ship The Sultana; it was the start of a trade mission that landed in New York on April 30, 1840. Although his voyage was not to a commercial success, it marked the point of successful friendly relations between the two countries, Oman and America, relations that influence America's political actions to this day (Eilts 1990).

In 1856, Hadji Ali "Hi Jolly" (later known as Philip Tedro), an Ottoman Turkish citizen with Syrian and Greek heritage, became one of the first camel drivers for the US Army- transporting cargo across American desert lands. His tombstone remains a national landmark, located in modern-day Arizona (Al-Ahari 2016).

From April 12, 1861 to May 9, 1865, 292 Muslims fought in the Civil War. Among them were Max Hassan, a Union porter, and Officer Captain Moses Osman, the

highest ranking Muslim who served with the 104th Illinois Infantry. When the civil war reached its end, the North's "scorched earth" policy destroyed schools, libraries, colleges, and other properties- erasing even more history.

On April 4, 1865 when Federal troops reached the University of Alabama campus with orders to destroy the university, Andre Deloffre, a modern language professor and custodian of the library, appealed to the commanding officer to spare one of the finest libraries in the South. The officer, being sympathetic, sent a courier to Gen. Croxton at his headquarters in Tuscaloosa asking permission to save the Rotunda. The general's reply was no. The officer reportedly said, "I will save one volume as a memento of this occasion." The volume selected was a rare copy of the Qur'an (Curtis IV 2010).

1900s to 2001

The late 1800s to the early 1900s brought the first immigrant Muslim wave, many of them single men of Bosnian, Syrian, Lebanese, Palestinian, Kurdish, and Turkish descent- men who were drawn to America in search for a better life, an economic opportunity, i.e. the American dream. Between 1921 to 1924, strict regulations were set that cut off the numbers of immigrants entering the country. Alongside policy was political rhetoric that contributed to the ongoing cultural climate of continuously omitting the experiences and efforts of black Americans and incoming immigrants of color. It led many Muslim immigrants to assimilate and intermarry- identifying with limited Muslim identity and self-labeling as Caucasian (Curtis IV 2010).

Yet at the same time these Muslim immigrants quietly created communal Muslim spaces- settling their roots primarily in the Midwest cities of Chicago, Detroit, and Dearborn. In 1930, the Nation of Islam began building a base, providing a route for the struggles of many black Muslims to be seen. In 1939, at the start of World War II, the political and cultural context finally started to shift for America; the war challenged the nation's current WASP centric society to transform into a more multicultural one. More emphasis was placed upon the foundations of equality and freedom, and this provided Muslim Americans an opportunity to show their religious values to coincide with American values. By 1947 the immigration laws allowed for an increased number of immigrants to enter United States, bringing many Muslim students and professionals to the country (Curtis IV 2010).

In 1965, The Immigration Act got rid of the nationality quotas, and another wave of Muslims entered the country. Still the Immigration Act limited annual immigration from the "eastern hemisphere" to 170,000, with a limit of 20,000 immigrants per country, and for the first time capped annual immigration from the "western hemisphere" at 120,000, without the country limit. In addition, a preference system was established for family members of U.S. citizens. Many Muslims came from India, Iran, Kuwait, Lebanon, Pakistan, and Palestine, again seeking refuge from political and religious crises. Some of them included followers of minority sects of Islam, in particular of Shia Islam subsects of Bohras and Nizaris. Soon after there was an influx of refugees from Afghanistan, Bosnia, Iraq, Somalia, and Sudan. Many of these folks settled into communities in Detroit, Chicago, Queens, Brooklyn, Los Angeles, and San Francisco.

The Muslim immigrants from all of these countries mentioned tended to be well educated students and professionals; they were educators, engineers, doctors, and independent businessmen. They created their own bookstores, cultural centers, mosques, and schools. And eventually, this led to a refreshed sense of self and a reclaiming of Muslim identity and space (Curtis IV 2010).

2001 to Present

By 2050 Muslim Americans are projected to comprise over 800 million individuals, 2.1% of the total population, becoming the second-largest religious group in the U.S. (The Association of Religion Data Archives 2014). Yet, the post 9/11 climate of anti-Muslim American sentiment has been part one primary driver of this study. There is a growing perception Muslims-Americans views and beliefs are irreconcilable with American ideals. Media portrayals work to perpetuate and instigate fear – showing that Muslims are violent and dangerous. With an ever-growing Muslim American population, there is a need to show the counter-narrative and show how Muslim-Americans, like many other marginalized groups, have contributed to American society at-large but their history and accomplishments have been repeatedly hidden from mainstream American society.

The next section takes a look at another historically disenfranchised group, those who suffer from mental illness, and a timeline of how America has included and also excluded this group into mainstream society.

Mental Health in America: A Brief Timeline

The National Institute of Health's U.S. National Library of Medicine ("History of Medicine Division at the National Library of Medicine" n.d.) provides a comprehensive history of medicine that helps summarize mental health practices in America including: mainstream perceptions and attitudes, cultural interpretations of mental illness, trends in psychiatry, and the subsequent national policies. The sections below summarize various time periods to provide a brief overview of how mental health systems of care have been constructed in America.

1700s: Mental Institutions

Beginning in the 1700s as early settlers came to America, the mentally ill were typically cared for by family members, and in severe cases they were sent to almshouses or jails. Stigma around mental illness in America began around this time as mental illness was seen as the result of moral or spiritual failing, which angered God and thus it was seen as a shameful punishment for those that were suffering from mental illness, and that shamefulness was extended unto their families as well (Szasz and Lyman 1968).

In 1752, Philadelphia Quakers organized the first formalized effort to care for the mentally ill by opening the Pennsylvania Hospital which had basement "rooms" that included shackles attached to the walls because Americans believed mechanical restraint was necessary in their hospitals. As additional space was needed for the Pennsylvania Hospital it opened suburban Pennsylvania Hospital for the Insane in 1856, a hospital that remained open, with various name changes, until 1998. In 1773 came the first

government-funded effort to provide mental health services, the Virginia legislature helped build and open a small hospital in Williamsburg, which is still in existence today as the Eastern State Hospital. After the founding of America in 1776, in 1792 New York Hospital attempted to open a ward that aimed to "cure" the mentally ill, which is still in operation today as the Payne-Whitney Westchester Hospital.

The trend of opening psychiatric hospitals continued with: the 1817 opening of the Asylum for the Relief of Persons Deprived of the Use of their Reason (called the Friends Hospital today), the 1824 Eastern Lunatic Asylum in Lexington, Kentucky (called the Eastern State Hospital today), by 1844 there were 25 public and private mental hospitals had been established, and by 1890 every state had built at least one publicly supported mental hospital. Simultaneously, as the 1800s produced many institutions, individuals were actively pursuing a better understanding of mental illness (NLM 2015b).

1800-1850s: Arise of Biomedical Understandings & Advocacy for the Mentally Ill

In 1812, Dr. Benjamin Rush, known now as "The Father of American Psychiatry," wrote and published the first textbook on mental diseases in America called, *Medical Inquiries and Observations upon Diseases of the Mind.* Although he pushed for biological understandings rather than moral understandings of mental health, his treatment methods were quite primitive. He believed that mental diseases were caused by irritation of the blood vessels in the brain and thus early treatment methods consisted

of bleeding, purging, hot and cold baths, and mercury, tranquilizer chairs, and a gyrator (NLM 2014).

In 1838, Dr. Isaac Ray published *A Treatise on the Medical Jurisprudence of Insanity* which served as an authoritative text for many years and gave Dr. Ray the capital of being known as the leading forensic psychiatrist of his time. Dr. Ray used his disposition to recommend statutory enactments that would secure the rights of the mentally ill and define the civil and criminal relationships of the insane.

In 1844, Dr. Amariah Brigham published the first journal that reported on the nature and varieties of mental diseases, methods of prevention, and humane methods to care for patients with mental illness (although he did also employ a cage-like "crib bed" and afterwards some type restraint was used in American institutions which trended until 20th century). The journal was called *The American Journal of Insanity* (*AJI*) then, and today is called the *American Journal of Psychiatry*.

In 1854, Dr. Thomas Kirkbride continued upon the trend of introducing humane methods of treatment for the mentally ill by publishing his book, which had a strong influence on the building and organization of mental hospitals, particularly state asylums which were known as "Kirkbride Hospitals" until the mid 20th century. Dr. Kirkbride's work was heavily influenced by a Quaker leader named Samuel Tuke whose family had instituted their own hospital where they utilized a "moral treatment", humane and kind, approach to care for their patients. Kirkbride's layout for the construction of new hospitals included: central building for administrative offices, kitchens, and staff living quarters with wings extending on either side, wards with wide central corridors, sitting

alcoves, single patient rooms, and small dormitories. Kirkbride was detailed in his approach to ventilation, heating, sanitary arrangements, and space for patient occupation and recreation, as well as having specific wards that classified patients according to their conditions (NLM 2015b).

By the 1850s and throughout the 19th century, a school teacher named Dorothea Dix became the leading advocate for the humane care of the mentally ill. In 1841, Ms. Dix visited a Boston jail to teach a Sunday School class where she saw firsthand the inhumane conditions people with mental illness were being subjected to, and this led to a lifelong journey of advocacy. Ms. Dix made visits to jails, almshouses, hospitals, and wherever else she found people with mental illness to be confined, documenting her findings along the way. She capitalized on “the interest and influence of prominent citizens and legislators to introduce written "memorials" into state legislatures in which she described the conditions she found.”

By 1850, Ms. Dix had created sufficient public support; “a bill was introduced into the Congress for federal lands to be apportioned to the states whose sale would provide funds to create or support facilities for the mentally ill.” In 1851, the bill passed in both Houses of Congress but was vetoed by President Franklin Pierce on the basis that “the care of the mentally ill was a state, not federal, responsibility.” Although the federal bill did not pass, Ms. Dix went on to help establish 32 state mental hospitals throughout the country (NLM 2015b).

The establishment of mental institutions, and the advocacy of those like Dr. Kirkbride and Ms. Dix led to the establishment of organizations like the Association of

Medical Superintendents of American Institutions for the Insane, which was organized by 13 people, including Dr. Ray, in October 1844- becoming the first professional medical specialty organization in the U.S. The Association of Medical Superintendents of American Institutions for the Insane (The Association), which is known today as the American Psychiatric Association (APA), originally aimed to build upon the Tuke family and Dr. Kirkbride's work of kind and humane treatment (but also the exclusion of women physicians). Their original mission was "to communicate their experiences to each other, cooperate in collecting statistical information relating to insanity, and assist each other in improving the treatment of the insane".

In 1851, The Association adopted 26 of Kirkbride's propositions for hospital design which served as official policy for 40 years. After 1870 Kirkbride's influence and the progress he had advocated for declined, by 1888, The Association voted to discontinue Kirkbride's propositions and the small hospital sizes (~250 beds) that Kirkbride advocated for grew to be large impersonal institutions (~10,000 beds) by the 20th century. Only a few states, like Wisconsin, maintained small county hospitals into the 20th century (NLM 2015a).

<u>1860s-1900s: Challenging of the Status Quo</u>

In 1860, a woman named Elizabeth Packard was forced to enter an Illinois state asylum, for three years, because she differed on theology with her clergyman husband. Illinois law at the time stated that husbands could request their wives be hospitalized, without any required evidence. Mrs. Packard eventually obtained a release by the

hospital, but upon arriving home her husband locked her up and prepared to send her to an asylum in Massachusetts.

In 1863, Mrs. Packard gained her freedom via a *habeas corpus* hearing in a local court, and then began advocacy work, organizing influential citizens and writing books on her asylum experience including *The Prisoners' Hidden Life* and *Modern Persecution: Or Insane Asylums Unveiled*. By 1880 she formed The National Association for the Protection of the Insane and the Prevention of Insanity, but The Association helped bring about the organization's demise within a few years. However, by 1869 Illinois legislature passed a law requiring a jury trial before a person could be committed. In 1872 Iowa enacted a similar law and other states took steps to safeguard patient rights as well. However, The Association strongly opposed jury trials, stating they were harmful to patients and thus these laws remained in effect for only twenty-five years.

In 1870, in regard to Mrs. Packard, Dr. John P. Gray, who became a leader in forensic American psychiatry for the second half of the 19th century, wrote, "This fascinating woman… by her feminine wiles had bewitched a whole legislature." Dr. John P. Gray served as editor of the *AJI* for 32 years which he used to introduce and build on the idea that "mental illness was due to physical causes that could be found in the brain, as opposed to the long-standing belief that mental illness was due to 'moral' causes."

Dr. Gray was the first to add a pathologist to his staff at the Utica asylum, being the first of mental institutions to do so, to further build upon the idea of mental illness being a biological illness. And when President James A. Garfield was assassinated by Charles Guiteau in 1881, Dr. Gray was brought to the prosecution and was served as

witness to the prosecution in stating that Guiteau was sane, perhaps an early move in declaring that it not only the "insane" that commit heinous acts.

Yet Dr. Gray's progressive thoughts did not extent to women, like Mrs. Packard. At the time women were not welcomed into the medical profession (Elizabeth Blackwell was the first women to graduate from medical school in 1847) and Dr. Gray, along with others, wrote letters to his governor opposing women physicians' employment when a MA state hospital/asylum first employed Dr. Mary Stinson in 1869. New York and Pennsylvania passed legislature that allowed female physicians to be employed, and after WWII in 1945 the number of women physicians increased significantly but still, they received less pay than their male counterparts, received little recognition, and were denied promotions- a trend that continues today.

Later in the 1870s, Dr. Edward Jarvis was actually concerned about the roles of race, ethnicity, social class, and immigration in relation to mental health and studied the 1840 Federal Census. Upon finding errors relating to the counting of mentally ill persons, he petitioned to Congress to revise procedures for gathering census data, entitled "Statistics of Insanity in the U.S." and he became known as the first American psychiatric epidemiologist.

In 1875, a British asylum superintendent named Dr. (Lord) John Bucknill, visited ten American asylums and wrote about Americans overuse of mechanical restraints. He challenged the use of mechanical restraint, disagreeing that it was necessary, which later was an argument that was applied to chemical/drug-induced restraints. This is still a controversial discussion taking place in today's government.

In 1877, Dr. Pliny Earle published *The Curability of Insanity* which challenged the "curability" rates of the public and private mental hospitals of the time which advertised 90% cure rates. Dr. Earle questioned the statistics which were published regularly in *The AJI* and pointed out "the lack of uniform standards of diagnosis and classification and the negligent manner of counting readmissions" and also set forth principles for "coercive admission to a mental hospital" as a legal procedure in "Project of a Law" which was approved by The Association.

In 1897, Dr. Bernard Sachs, who became known as "The Dean of Neurology" stated his opposition to psychoanalysis which he said was "illogical, unsubstantiated in science, and possibly dangerous when used with children". He had worked with Freud and instead encouraged for more more of biomedical influence in the field of psychiatry, advocating for psychiatry to merge with neurology into "neuro-science, and thus for both fields to work synergistically for the care of their patients (NLM 2015a).

1900s-1950s: National Interest in Mental Health Arises

In 1908, Clifford Beers' autobiography, *A Mind That Found Itself*, put forth his personal struggles with mental illness and the conditions he had endured in asylums. Later that year he founded the Connecticut Society for Mental Hygiene to lobby and research ways to improve the lives of the mentally ill.

By 1909, just one year later, the society evolved to become the National Committee for Mental Hygiene, or "the Committee" - which was then renamed in 2006 to the Mental Health Association (MHA - a prominent and active organization today).

In 1910 the Committee succeeded in fostering prevention, early intervention, and treatment of mental illness with the creation of over one-hundred child guidance clinics in America.

By 1917 the Surgeon General of the United States requested the Committee to draft a “mental hygiene” program for the Army and the Navy in preparation for the First World War; and by 1920 the Committee produced a set of “model commitment laws”, which were later incorporated into several states’ statutes.

In the 1930s the Committee held the first “International Congress on Mental Hygiene” in Washington D.C., which brought together 3,000 individuals from forty-one countries. Likely this convention aided in the 1946 “National Mental Health Act”, passed by president Harry Truman, which allocated government funds towards research into the causes/treatments for mental illness and created the National Institute of Mental Health.

1949 became the launch of Mental Health week, later to become Mental Health month, and then in 1955 Congress funded Commission on Mental Illness and Mental Health (NLM n.d.).

1960s-Present: Deinstitutionalization and its Effects

Prior to the mid-1950s inpatient institutionalized mental health was the primary mode of care; while this increased patient access to mental health services, the asylums provided poor conditions and drew criticism for their harsh methodologies.

The 1960s push for deinstitutionalization was a movement from “asylum-based” mental health care towards community-oriented care, which would aim to provide more personalized care to patients. In 1963, President Kennedy and Congress passed the “Mental Retardation Facilities and Community Health Centers Construction Act”, which closed state psychiatric hospitals and provided federal government funding for the creation of 2000 community-based mental health centers (CMHCs) to be built by 1980. Only 754 centers were in operation by 1980.

By 1981 the era of deinstitutionalization reached its conclusion with President Reagan’s Omnibus Budget Reconciliation Act. It rescinded the federal funding for CMHCs, turned other federal aid to the states into block grants, and cut the dollar outlays by as much as 30 percent, and left the states with broad discretion over how to spend the money; this left many of those with mental illness homeless or imprisoned.

While the goal of deinstitutionalization which is to improve treatment and quality of life for the mentally ill, is a goal shared by most- the resulting reality is debated. Judge Steven Leifman has stated that while the federal funding was authorized, it was never appropriated (Perez, Leifman, and Estrada 2003). In the 1950s over 560,000 patients

were institutionalized and by 1980 only 130,000 remained institutionalized. While there were 339 state psychiatric hospital beds per 100,000 people in 1955, by 2000 this number became 22. Judge Leifman argues that "We never deinstitutionalized. We trans-institionalized. We moved people from hospitals not to community support but to jails and then give them criminal records." He argues that this has only increased the stigma of mental illness and additionally compounded the stigma by adding the stigmatized term of "criminal". This makes it infinitely harder to get housing and employment and increases the likelihood that these individuals will cycle through the criminal justice system. Today, with lack of funding and options of mental health care, we continue to struggle with the mistreatment and maltreatment of Americans with mental illness.

Mental Health & Muslim-Americans: What Current Literature Suggests

"It's so loud inside my head, with words that I should have said.
I think that all the silence is worse than all the violence.
-Lupe Fiasco

To be visibly "Muslim" when vehement campaigns like "Islam Hates Us!" fuel upon post 9/11 rhetoric that attack the Muslim American community but has led to collective community trauma. Muslims are experiencing stressful interpersonal events after the 9/11 attacks related to being Muslim; these include but are not limited to anti-Muslim comments, undergoing special security checks in airports, facing discriminatory acts, and being verbally harassed (Abu-Raiya, Pargament, and Mahoney 2011).

Studies show how such rhetoric has also affected communities who are not Muslim, but are perceived to be Muslim by society at large, and so they too are

discriminated against. Sikhs have been the biggest victims of anti-Muslim hate crimes and Arab Americans, regardless of faith, report more racial/ethnical discrimination (Abdulrahim and Ajrouch 2010).

This leads to how trauma has seeped deep into society, affecting even those who could by many standards be known to easily assimilate. A recent study looked at how 9/11 affected American Muslim physicians (AMPs) and reshaped their individual and collective response, how it changed their sense of collective identity. The results are quite devastating, showing the mistreatment and prejudice faced by many AMPs has left permanent impressions on their sense of identity (Abu-Ras, Senzai, and Laird 2013).

Using a grounded theory approach to examine the identity development of Muslims growing up in the age of the “war on terrorism,” Saedi’s study results show how post 9/11 anti-Muslim rhetoric has affected not only the wellbeing of Muslim-Americans but it has also significantly impacted the mental health of Muslims around the world, resulting in decreased wellness for many Muslims across the globe (Saedi 2012).

One particular study that investigated the above claim that Islamophobia sentiments from America are impacting the world, was set in New Zealand. The researchers were studying the perceived religious discrimination and three facets of Muslim identity (psychological, behavioural, and visible) as predictors of psychological well-being (life satisfaction and psychological symptoms) of 153 Muslim women. Results indicated that although visibility (wearing hijab) was associated with greater perceived discrimination, it also predicted positive psychological outcomes. Further analysis revealed that the psychological (pride, belongingness, and centrality) and

behavioral (engaging in Islamic practices) facets of Muslim identity moderated the relationship between perceived religious discrimination and well-being, so engaging in Islamic practices buffered the negative impact of discrimination (Jasperse, Ward, and Jose 2012). This research contributed to a field of growing research on how religious identity, even when under attack, can serve as a protective barrier to health (Padela et al. 2012; Asvat and Malcarne 2008).

Current literature on Muslim-Americans' lived experiences utilizing comprehensive health care, including accessing care for mental wellbeing is extremely limited. The increasing Muslim population in America calls for an increase in the need for mental health services. The author considers techniques for incorporating ethical and effective Islamic beliefs and practices in the therapy processes (Hamdan 2007).

To effectively understand and meet the under-acknowledged mental health needs of the growing population of Muslim Americans begins with an examination of individual health narratives- detailing the intricate, intimate, and varied ways that individuals may incorporate multifaceted, formal, and informal modes of healing. Individual narratives can then come together to provide a collectivist narrative. My exploratory study aims to elicit and analyzes health narratives of Muslim Americans in the Greater Boston Area to understand how Muslim Americans discuss, understand, and interpret the concept of comprehensive mental/emotional health.

As I delve into following chapter, exploring perspectives of emotional well being and resource utilization within the Muslim American community, I ask of you to keep

one thing in mind: This is a two piece journey: understanding the ways in which the Muslim Americans, as individuals, and then Muslim Americans as a collective (although extremely diverse in thoughts, beliefs, and actions) define, navigate, and undertake issues related to mental/emotional health. This requires understanding individual narratives, finding commonalities and differences, and ultimately leading to an effort which gives voice to a community that has historically stayed quiet, but that *silence is worse than all the violence.*

CHAPTER 3: METHODS- FROM A QUESTION TO A PROCESS

"It isn't the mountains ahead to climb that wear you down it's the pebble in your shoe -Muhammad Ali"

Creating the Study:

The Question:

How and why do Muslim Americans define and utilize emotional (mental) health resources and services?

My topic of interest- mental health within the Muslim American community stemmed from personal experiences. The conversations (or lack of) taking place around mental health were limited, both in volume and approach. I wanted to understand what was limiting these conversations, and my hypothesis was stigma. To gain a deeper understanding of stigma I would need to understand how, where, and what type (of stigma) played a role in limiting my community's progress in mental health.

While the stigma surrounding mental health in the American community at-large is abundant, my own experiences and interactions as a part of the Muslim-American community highlighted the extent to which stigma was exacerbated and multiplied. To even approach the topic of mental health, I would not be able to walk through a door, but instead prop open a window. Thus, I decided that window would be "emotional health", an in vivo code, a more culturally accessible term that could allow initial access into discourse around mental health.

In order to have a comprehensive outlook on addressing the stigma surrounding mental health, I aimed to understand how historical and political contexts contributed to

the landscape of mental health in America and specifically for my topic, how did the post 9/11 growing anti-Muslim sentiments impact the mental/emotional health of the Muslim-American population.

Collecting Data Summary:

To study Muslim Americans as a collective is difficult. Similar to the woven cultural fabric of America at large, Muslim Americans hold a spectrum of various beliefs, behaviors, ethnicities, societal expectations, preferences, and socioeconomic classes, making them amongst the most diverse minority groups in America today.

However, nearly 60,000 Muslim Americans reside in the Greater Boston Area, which provided a sufficiently diverse and appropriate landscape to conduct this research. My personal reflections and participant observation at two different field sites led towards a grounded theory approach in developing my research question and collecting data. Through social-network/ respondent-driven and judgment sampling, I ultimately recruited 10 participants, 5 men and 5 women. Although I did not intend to interview only Muslim-Americans with advanced degrees, the ten participants who were ultimately willing to be part of the study all held at least a Master's degree (One initial speculation was that this in itself was an early testament to the amount of knowledge one had to attain before they were willing to be involved in any kind of dialogue around mental health).

The resulting interview process included participants filling out 1) a demographics survey and 2) A self-reported combined Review of Systems/ PHQ 4, questionnaires commonly utilized by health providers to screen for conditions such as

anxiety and depression. Then the semi-structured interview began and lasted between 1.5 to two hours; the data collected from these interviews contributes to the majority of my narrative and discourse analysis.

Collecting Data Process:

When I began my research process in early 2014, it was hard to imagine how I would transition research questions into a process- what would it take to delve into the type of elbow deep research I was aiming to conduct? With the help of my faculty advisors I began creating "formal" interactions with the Greater Boston Muslim-American community, via an internship process. I had expected it to be a relatively smooth sailing venture, anticipating a few bumps here and there, but I certainly was not anticipating what would follow in the coming years.

I started off connecting with a local Muslim leader who ran an organization aimed at providing Muslim youth, particularly those of Somali descent, a place to further enhance their growth, be it emotionally, spiritually, or socially. The organization was relatively new and needed much assistance, yet my presence, at best, seemed to be a burden rather than a role fulfilling the needs of the organization:

"I am not really sure what I am supposed to be doing at the Development Center[1]. I spoke to Mary[2], again, but haven't really gotten a good view of what it is they want me to do. I just feel like everything is so chaotic right now and I have no clear direction of what I am doing or how to do it.

I met with Sajida again too, but it seems like she thought I had come here to tutor (which is not what I want to do) but she did say Mahmud had some ideas for me and

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[1] De-identified Organization Name
[2] Pseudonym

when he returned from Hajj he would fill me in, but I haven't heard from him yet. I texted him again this morning, I guess I will just keep trying.

(Fieldnotes: Fall 2014)

I was working in a position analogous to the role of an administrative assistant which led to constant interactions with paperwork and quite limited interactions with people. The non-profit was severely understaffed and supremely overworked; they had to get things done and my questions were rather a nuisance. Their need was in getting things done. Volunteers were needed, but in the capacity of high school tutors- and this just did not allow for pursuit of my research goals.

However, I did have a few interactions with some of the older Muslim women who would come to volunteer as after-school caretakers. When I asked them what brought them to the organization- it was the need to keep their community close:

> *"Our families they came here, they lost their families, their Somalia, and now we feel like we lose our families here too when our children go astray."*
>
> *(Fieldnotes: Fall 2014)*

This statement represented to me much of what the organization was doing, trying to keep their children close to home, trying to create a physical place where the old and the young could connect, a place that could bridge the gap between two cultures. And this, was not something I was hearing for the first time. This sentiment was not shared only in the Somali community, but also in the Pakistani community, the Libyan community, and so on.

> *"I am going to speak with Sameera*[3] *next week about what I am looking to do, where in the Muslim community should I start out? Where can I build rapport within the community? I'm just feel too confused, frustrated, and overwhelmed in*

[3] Pseudonym for the office worker

the moment. No one wants to talk to me about mental health. They look at me like I have just spit on their face."

"I know the purpose of the internship is to build rapport, but I don't even really know how that is going to happen right now. I do think that the Development Center will be beneficial in gaining access to older and younger generations as I would like to study the discrepancies between immigrants and their children on their views of mental health.

I want to know how views have shifted/been passed down from older generations to younger generations and what does this mean in terms of mental wellbeing, for all generations, as a community? How do these perspectives influence care and physical health status, overall health status? Ultimately, I want to find ways to reduce stigma so I can even say mental health without everyone "freaking out".

I just don't know if the Development Center is the place for me to do this. Mary says to speak with the older generations, but I need translators and I just don't think I can build rapport fast enough for a master's thesis project that will allow me to access the information I seek. Having a third party just seems like it will be detrimental, and responses will not be as candid, if even provided at all. I just don't think people will be receptive to this, me coming in as a 2nd generation Pakistani American...and we read all this interviewing stuff in Methods class and I think I'm just entering a space that I am not going to be able to navigate effectively. Especially being Muslim, I feel like that will increase the ambivalence. Small community dynamics and what not."

(Fieldnotes: Fall 2014)

My time at the Development Center, although not what I had planned, was indeed crucial towards the development of my research process. While I started my internship knowing that I wanted to gain a better understanding of mental health perspectives of Muslims Americans, paying particular focus on the experiences of individual Muslims- it took me some time to figure out singular question I *did* want to understand.

It was here that I decided I would use the term emotional health, and formulated five broad questions:

1. How do Muslims in the Boston Area discuss, understand, and interpret the concept of emotional/mental health in general?

Do they discuss it? In what capacity? To what extent?

2. What issues relating to emotional/mental health do individuals in this community report?
   Is there a prevalence of certain issues? Of certain illnesses?

3. How does this community of Muslims react when issues related to mental health arise?
   Do they address these issues? Do they seek and utilize mental health resources? if so, in what ways? What would they consider to be a mental health resource?

4. How do perceptions related to mental health differ for individuals with regards to particular demographics?
   How do factors like immigration/generational status, age, gender, etc. create differences/divides in perceptions, access, and utilization?

5. Do perceptions of mental health have a correlation with individuals' overall health status?
   In what ways? Are there unexpected idioms of distress? What is the willingness to discuss physical vs. emotional wellbeing?

These questions led me towards my leading research question: *How and why do Muslim-Americans define, and utilize emotional (mental) health resources and services?* To get to the crux of this question, I needed to recruit willing participants, which was simply not happening at the Development Center. I communicated these concerns to the organization's director and he suggested me that I instead collaborate with the Blue Mosque[4] where I might have better luck engaging in the discourse I was seeking.

Participant Observation:

At the Blue Mosque I started out as a normal volunteer. I sat at the entrance desk and answered mostly generic questions about different meeting spaces, prayer times,

[4] Pseudonym

bathrooms locations and so on. Even though, I wasn't much more than a talking pamphlet, I was at least a little useful; a full bladder is a pretty serious thing, and I could point you toward the bathrooms. And when I wasn't saving folks from exploding bladders, I spent my time making three-foot tall frenemies who tended to be two decades younger than myself and gladly obliterated me in very sophisticated iPhone games (i.e Subway Surfers) while their parents offered prayers. As the winter of 2015 approached, I moved from the bright, buzzing welcome table to a less glamorous one, tucked away behind some cardboard boxes in the Blue Mosque's central office. Here, I spent most of my time working with administrators, logging financial logistics for the upcoming Ramadan. Although I was now spending time with individuals my own age, I was initially limited in the depth of our interactions. In the beginning of the transition I primarily discussed excel sheets that told us how many chairs and tables had to be set up, but as I spent more time in the office and the staff and I became acquainted, our conversations grew in substance beyond event planning.

This was the time I got to spend with *my* community. This was the time I didn't have to play the position of the researcher. This was the time I went from being Kanwal, another graduate student who needed volunteer hours, to Kanwal who had left her loved ones behind and moved to Boston because she hoped to build a better future- and this was the piece that resonated with many others who walked through those masjid doors.

Eventually people came to understand my goal- not one that aimed to pry or prod, but simply to connect and understand. As I built connections with those around me, I was let into their lives, into the community. That is when my fieldwork really began.

We began to discuss the ways in which we felt obligated and responsible to make the world a better place. We talked about the ways in which Islam taught us to do this, the subjects we chose to study, and why. We talked about my research, we talked about taboos, about stigmas, about familiarity and pain. We talked about how the khutbahs that taught us stories about our faith, focused on staying strong, not about saving face. We talked about how the FBI folks would just barge in to our house of prayer, we talked about their policies on countering violent extremism, and we talked about the war on terror. We talked about Syria, Palestine, Sudan, and Somalia. We talked about Kashmir and Afghanistan. We talked about how the news showed us only one depiction. We talked about how people treated us when we crossed the streets in abayas. We talked about how tired we were feeling and having to just keep going.

Fieldwork was one of the most challenging, engaging, and rewarding experiences I have had to date. From fieldwork, I gathered experiences through participant observation, and learned to communicate those experiences through ethnography, "the scientific description of the customs of individual peoples and cultures". In the field of medical anthropology much of the work done by the researcher is ethnographic- which is a two-pronged project.

The first prong of ethnography is the process of doing research. It is the observations, the notes, fieldwork, the role of the researcher, and his/her investment in *actually* engaging with participants and community. It is the art and science of observation which allows researchers the opportunity to examine problems or phenomena

in real time, utilizing real-world methodologies, and learning to recognize the always present nuances between what people say and what they do.

The second prong is ethnography as the final product- the result of that research which showcases the first prong. An ethnographer has to learn to listen and observe in a nondirected way, taking in the experiences of one population- learning the ways in which individuals within a specific population interpret and take meaning from particular experiences- and then the ethnographer is given the task of translating those lived representations of one group, for another. Ethnography is a practice of self-reflection, requiring one to actively work against internal biases, to understand one's own role and attitudes, via positionality (their *own* position relative to the research- recognizing there is no such thing as complete neutrality), and to acknowledge the vitality of such reflections in order to make the closest attempt to understand the lived experiences of others.

What makes an ethnography powerful is that it is emic; the analysis stems from the perspective of one who actively participates in what is being studied. The one who writes about playing ball, has been running out on the court, dribbled the ball, passed to teammates, learned from a coach, argued with a referee, screamed from the benches, won and lost- he/she was an active participant and not simply a casual observer from the sidelines. Through an array of encounters, ethnography plants the seeds of observation, fertilizes it with descriptions, and reveals the emerging analyses- the critical categories, the theories, the overall meanings.

I had not imagined fieldwork to create such a profound experience. I learned that the most important thing was not my role as researcher, not even my role as a community

member, but my role as another human being that shaped the results of my fieldwork. It allowed me to be vulnerable with my participants, and that eventually led them to be vulnerable with me. Creating trust, allows us the opportunity to hear one another's stories, our truths.

> *" This week has been extremely difficult. Yesterday we had a funeral prayer for a mother who had lost her two-year old child, and the today there was a family who lost their adult son. To suicide. No one is talking about it, I don't even want to write about it, my heart is heavy. I just came back from the Muslim Mental Health Conference, I was on a "high", elated that our community was doing work to combat stigma. But it feels not nearly fast enough, not fast enough when people are dying, every day." (Fieldnotes: Spring 2015)*

Formalized Data Collection

With regards to sampling, Muslim Americans in the Greater Boston Area are a highly visible group. There are nearly 60,000 Muslim Americans in the Boston area and over 120,000 in the state of Massachusetts[5]. So, when thinking about such a significant population in terms of location and interviewing for a pilot study regarding intensive critical case studies, purposive sampling seemed to be the best fit.

Due to the type of response from my community and affirmation of my work I would align my qualitative research in the context of informal community based participatory research (CBPR). CBPR is very much a "partnership" approach; the community with which I am working will benefit from the end result of the research, but

[5] Provided by MA CAIR's John Robbins

most importantly they have had a significant hand in how my research study was designed, placing a special focus on methods before theory. I was told by my community members that starting with a proposed theoretical framework was dangerous and would not fully incorporate the needs of the community, nor would it be practical.

I began formalized data collection in the summer of 2015 and had originally planned to do "formal participant observation" along with interviews. However, because my research population happened to be my own community, I ended up conducting "informal participant observation" by constantly observing conversations that would ensue after I brought up my research topic. This included observations of how people reacted to me conducting research on mental/emotional health, their willingness (or not) to participate, and their hopes for what such a project might accomplish. These conversations primarily took place in quiet spaces like mosques, cafes, university lounges, and in places of residence. Data collected was always de-identified immediately after.

Data Recruitment

All of my research recruitment documents, surveys, and consent forms indicated to potential parties that their participation is completely voluntary; this was a point I reiterated to participants multiple times. I had the advantage of "belonging" to the Muslim population, which helped to alleviate some issues of suspicion and mistrust and also helped lower sampling biases that might otherwise play a role with methods such as snowball sampling. Purposive/judgment sampling in conjunction with social network/

respondent-driven (snowball) recruitment methods were used.

My internship and participant observation at the Blue Mosque allowed me to feel confident in doing this work. There was some pushback from older generations but overwhelming support from younger adults, who emphasized and applauded the necessity of this work. The common consensus amongst the Muslim-American millennial generation is that emotional/mental health is a topic that our community has swept under the rug for too long and now it is time to address it. I believe for this reason, gathering of formal data became easy for me after my internship; instead of struggling to recruit participants, there was an overwhelming number of willing participants.

I recognize that my role as a researcher, and as a community organizer, creates an unequal power dynamic and that can possibly contribute to potentially uncomfortable realities. I have gone through various hoops to verify my participants' comfort and confidence. All data collected is presented as anonymous and de-identified. The information gathered in each step of this study did not pose a risk to academic standing, employment, reputation, or any other harm to the participants. With regards to members of the Boston university population, all individuals who happened to see/ hear recruitment material were made aware of the nature of the study and were self-selected for participation, avoiding all risk of coercion. Given that I was recruiting from the communities to which I belong, pains were taken to clarify that participation in this study was entirely optional, and one should only participate if they are entirely comfortable doing so; a decision to participate or not will in no way affected personal relationships, future collaborations, etc. None of the participants had a student/mentor or

employer/employee relationship with me, the research investigator. Finally, because of the nature of social network respondent-driven (snowball) recruitment methods that were used, many participants choose to initiate contact with the investigator (me) and/or volunteered to be interviewed based on hearing about the study from another participant. Again, all data presented in following chapters is anonymous and de-identified. For further protection of my participants I have changed some settings, removed any remotely identifiable information, and thoroughly de-identified every participant. In the hopes of this research being informative, I cannot take a chance that my research is destructive in any way, unintentionally or not, to the lived realities of my participant(s).

Conducting Interviews

Originally, I hoped to conduct 35 short (20-30 minute) interviews, as I had over 35 willing participants. After conducting two interviews, both nearly two hours long, I recognized that in the interest of time I could conduct 10 in-depth individual interviews- five men, and five women.

Thus, the summer of 2015 mostly entailed conducting interviews. It just so happened that I conducted my fieldwork during the month of Ramadan and it is important to keep in mind that what respondents noted about emotional/mental health during Ramadan might bring a heightened sense of belonging, support, and self-reflection.

I met twice with participants. The first time we met would be over a cup of tea, a cultural gesture of comfort within many Muslim American communities. The idea behind

this being when you sit together, you drink tea, and you talk about issues of matter. The tea helped calm my own nerves, and I believe it helped put my participants at ease as well.

After a few sips we would review the details of what my study including the associated demographics survey, the review of systems/PHQ4, and the interview guide. I offered participants the opportunity to ask any necessary questions, wanting to make sure they had time to truly consider if they wished to be a part of the study.

The second time we met, the actual interviews took place, usually over a meal after, after fast was opened. The interview process typically began with me reading a verbal assent statement and answering any remaining questions about the interview guide or any other aspect of the study.

Then each participant was asked to complete the anonymous demographic survey and the review of systems/PHQ4 that contained a few general questions about participants' perceptions of their own physical and mental health.

These surveys were synthesized from more than a dozen medical education sources to create a simple but standard template "Review of Systems" that might be used in many primary care clinics, and a PHQ 4 which is a simple mental health screening questionnaire commonly used by healthcare professionals.

The review of symptoms/PHQ4 was used for triangulation purposes and reported directly to me, the researcher, by participants- thus was not subject to HIPAA. The survey contained a disclaimer making clear that it is was not intended to diagnose or treat any medical condition. I also voiced this disclaimer.

All participants were also given Muslim Mental Health referral sheets- in case the survey brought up any concerns needing professional medical attention and/or care. Interestingly, every participant refused the referral paper before even beginning the interview.

Figure 1 Demographic survey

Date: ______/______/______

WAIVER OF CONSENT – By completing this survey you indicate your assent to having the anonymous or de-identified data you provide used for research purposes. This is an optional survey. This research study is gathering anonymous information about issues related to accessing comprehensive healthcare services for Muslims living in the U.S. The anonymous information you provide will be hopefully used to make it easier for other Muslims to access comprehensive services. **Please Check One of the following boxes, or leave the survey blank if you do not wish to participate:**

____I do want anonymous information from this survey to be used for research related to improving comprehensive health care services for Muslims living in the U.S.

____I do NOT want anonymous information from this survey to be used for research related to improving comprehensive health care services for Muslims living in the U.S.

Q1: Age?
- ❑ 18-29
- ❑ 30-49
- ❑ 50-64
- ❑ 65+

Q2: Gender?
- ❑ Male
- ❑ Female
- ❑ Other

Q3: Ethnic/Racial Identity?
- ❑ African American/African/Black/Caribbean
- ❑ Asian/South-Asian
- ❑ Caucasian
- ❑ Hispanic/Latino
- ❑ Native American
- ❑ Pacific Islander
- ❑ Other

Q4: What is your parent's country (or region) of origin?
- ❑ ____________________

Q5: What is your generational status:
- ❑ (1st) Born outside of the U.S.A and arrived at age 15 or later
- ❑ (1.5) Born outside of the U.S.A and arrived between the ages of 6-14
- ❑ (2nd) Born outside of the U.S.A and arrived before the age of 6
- ❑ (2nd) Born in the United States but either one/both parents not born in USA
- ❑ (3rd) Born in the United States and both parents were born in the USA

Q6: When did you come to the U.S.?
- ❑ ____________________

Q7: When did you come to Boston?
- ❑ ____________________

Q8: Where did you primarily grow up?
- ❑ ____________________

Q8: What kind of region was it?
- ❑ Urban
- ❑ Suburban
- ❑ Rural

Q9: What is your highest level of education?
- ❑ Primary School
- ❑ Some High School
- ❑ High School Graduate
- ❑ Some College
- ❑ College Graduate
- ❑ Graduate School/ Professional School

Q10: In what country was your education primarily received?
- ❑ ____________________

Q11: What is the highest level of education you have received in the U.S.?
- ❑ Primary School
- ❑ Some High School
- ❑ High School Graduate
- ❑ Some College
- ❑ College Graduate
- ❑ Graduate School/ Professional School

Q12: What is your annual average income?
- ❑ Less than $20,000
- ❑ $20,000-$34,999
- ❑ $35,000-$49,999
- ❑ $50,000-$74,999
- ❑ $75,000-$99,999
- ❑ $100,000+

Q12: What is your family's average household income?
- ❑ Less than $20,000
- ❑ $20,000-$34,999
- ❑ $35,000-$49,999
- ❑ $50,000-$74,999
- ❑ $75,000-$99,999
- ❑ $100,000+

Q12: What religious practices within Islam do you identify with?
- ❑ Just Muslim
- ❑ Sunni
- ❑ Shia
- ❑ Sufi
- ❑ Ismaili
- ❑ Ahmadiyya
- ❑ Other

Q13: Which is most applicable to you?
- ❑ Born into Islam and raised Muslim
- ❑ Converted to Islam
- ❑ Other (Please specify) ____________

Figure 2 PHQ-4 Questionnaire

Disclaimer: Anonymous or de-identified health symptom information you provide in this self-reported health survey will NOT be used to provide medical attention, diagnosis, or aid in any way. It is solely for research purposes. If completing the survey brings urgent or chronic concerns to your attention, please tear off the form and use the provided referrals to seek care!
Referrals for medical care are listed on a separate form attached to this survey.

Have you experienced any of these symptoms within the last year?

General
- ☐ Change in Appetite
- ☐ Change in Weight
- ☐ Overall Weakness
- ☐ Lack of Energy/Fatigue
- ☐ Anhedonia (Lack of enjoyment)

Eye/Ear/Nose/Throat
- ☐ Vision Loss
- ☐ Hearing Loss
- ☐ Difficulty Swallowing
- ☐ Sinus/Allergy Symptoms
- ☐ Neck stiffness

Cardiovascular
- ☐ Chest pain
- ☐ Palpitations / Irregular Heartbeat
- ☐ Orthopnea (Shortness of breath lying down)
- ☐ Paroxysmal Nocturnal Dyspnea (Waking up at night with shortness of breath)

Respiratory
- ☐ Dyspnea (Shortness of breath)
- ☐ Pleurisy (Chest pain with breathing)
- ☐ Tightness in chest

Gastrointestinal
- ☐ Abdominal pain
- ☐ Nausea
- ☐ Reflux/ Heartburn
- ☐ Irregular/Difficult Bowels

Urinary
- ☐ Incontinence
- ☐ Urinary Frequency
- ☐ Urinary Tract Infection

Reproductive
- ☐ Genital Pain
- ☐ Genital Discharge
- ☐ Amenorrhea(Lack of periods)
- ☐ Menorrhagia (Heavy Periods)
- ☐ Irregular Periods

Neurological
- ☐ Headache
- ☐ Weakness
- ☐ Dizziness
- ☐ Tremors
- ☐ Head Injury
- ☐ Memory Loss
- ☐ Insomnia
- ☐ Daytime Sedation (Frequent Naps)

Psychiatric
- ☐ Anxiety/ Nervousness
- ☐ Depression
- ☐ Disinterest/Apathy
- ☐ Irritability
- ☐ Rapidly changing moods
- ☐ Intrusive thoughts
- ☐ Paranoia/Suspiciousness
- ☐ Hallucinations
- ☐ Loss of good insight

Psychiatric Continued…

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	☐ 0	☐ 1	☐ 2	☐ 3
2. Not being able to stop or control worrying	☐ 0	☐ 1	☐ 2	☐ 3
3. Little interest or pleasure in doing things	☐ 0	☐ 1	☐ 2	☐ 3
4. Feeling down, depressed, or hopeless	☐ 0	☐ 1	☐ 2	☐ 3

For the symptoms you marked off, have you sought treatment within the last year? ☐ **Yes** ☐ **No**
If yes, with whom/what modes of treatment did you utilize? ____________________
____

For the symptoms you marked off, did you self-treat within the last year? ☐ **Yes** ☐ **No**
If yes, what methods did you use to self-treat? ____________________
____

Figure 3. Semi-structured Interview Guide

Semi-Structured Interview Guide

(Not all participants will be asked all of these questions, but prompts from each category will be used)

Clarification

- Confirm verbal assent for participation
- Choose pseudonym
- Any questions for me?

Background/ In-Depth Demographics:

- How long have you lived in Boston?
- Where did you grow up?
- Can you share your immigration story with me? (If applicable)

Islamic Perspectives

- What religious practices w/in Islam do you practice, if any?
- Where you born/raised Muslim/ Did you convert to Islam? (For converts: Can you share your story with me?)
- Do you think you are visibly/audibly identified as Muslim? (By name/way you dress)

Islam in America

- How would you define the term religious?
- How religious do you consider yourself to be?
- What parts of Islam are most meaningful to you?
- How does Islam play a role in your everyday life?
- How do you feel about being Muslim and living in (the) Boston (area)? (What is good about it? What is hard about it?)
- How do you think Muslims are viewed in (the) Boston (area)?
- How important is community support? Islamic community support?

Emotional Health

- How would you define the term emotional health?
- Do you think it is something worth discussing? If so, why?
- Is emotional health something you regularly discuss? If so when? With whom?
- If you feel comfortable, what have been some of your experiences with relation to emotional health?
- What role does Islam play in your views of emotional health?
- Does the Islamic community play a role in your emotional well-being? If so, in what ways? (Positive or negative)
- Do you think your views on emotional health differ from that of your parents (or children's')?
- Do you think your generation would share similar views as yours on emotional health?
- If someone in your family or circle of friends were having emotional problems, what would you advise them to do? Where do you think they should go for help? Have you known anyone who has done this? How did it work out?
- What about mental health? How do you feel about that term?

Health Care:

- How do you think the health needs of Muslims are similar to and different from the needs of non-Muslims?
- Who do you see for your physical health needs? What do you normally do to care of your physical health?
- Who do you see for your emotional health needs? What do you normally do to care for your emotional health?
- What has your experience been like in having your health needs as a Muslim addressed?
- What health needs do you think need to be addressed more?
- Is there anything else you would like to share with me?

Nearly all of the interviews lasted between 1.5 to 2 hours. Reflecting back upon the hopes of conducting 35 interviews- it would have been near impossible in the scope of a master's thesis. After 10 interviews I was mentally and emotionally exhausted. For many of my participants it was the first time or one of very few that they were sharing some of their stories of pain, suffering, and heartbreak. These interviews tended to unintentionally serve as counseling sessions for many participants. When asked "What do you do for your mental health needs?" one participant responded, "I talk to you." That statement serves as a testament to how immersive this experience became for me, with more depth and difficulty than I could have imagined.

Leaving the Field Site

In the summer of 2015 I discovered just how immersive of a process research really is. Starting from participant observation at the Blue Mosque, my participants and I didn't just talk in secret spaces, between four white walls. We talked outside, on walks to grab food, on benches in parks, and on the dock with our feet in the water. I know it sounds a bit romantic, like a tale of passionate summer love, but perhaps in some ways maybe that is what it was.

"As we were walking to get food the other day, Yasmin[6] *and I discussed the ways in which people pronounce our names, how people looked at us when we walked to the mosque in our traditional garb, how all of our friends seemed to marry within the same ethnic groups because they were most like us because "looking for proper support within our communities", we talked about why we were at the mosque, why we wanted to help our communities, and how we were doing that...starting with being at the Blue Mosque "*
(Retrospective Field Notes: Spring 2015)

[6] Pseudonym

And as with many summer flings, when the cold seeps in and the leaves begin to fall, the lovers begin to part ways. I didn't want to formally leave the Blue Mosque, but I did. I left my desk and my excel sheets behind, in some ways very grateful to have signed a contract that stated the guidelines and bounds of my formal stay.

Summer love is exciting because it is all consuming, it drowns you in emotion, and mine overwhelmed me with a trove of information and stories, with collective feelings of frustration and fear. For the Blue Mosque specifically, its role as a community space shows up in many places as an influencer of access and for the role it plays for an entire community's wellbeing.

As time passed by, my days at the Blue Mosque became limited: perhaps a Friday prayer, a halaqa, or a talk by the mayor- but this place will always remain ingrained in my brain as the first place that recognized the importance of this work. The daily conversations on what it means to be Muslim, what it means to be American, what it means to be the daughter of immigrants, and how the various influences of community and identity labels play a role in our everyday behavior and actions, are all pieces of conversations expanded upon in the following chapters.

I left the physical space behind but continued to carry with me love and respect for the people I had met, the responsibility to make sure their stories are told, their trust is not taken for granted. It is time to translate those stories, to lift up my participants and their suffering, and finally, to finally let their voices be heard.

Conducting Analyses

As I left my field site, the Blue Mosque, and started my own ethnographic writing, it was vital for me to preserve and continue relationships with my key informants. Research morphed from the academic sector over to the personal one. Much time was spent contemplating the issues and ideas my participants brought up and in what ways I could use my role as a researcher to alleviate some of these issues:

> *"Summer was a complete immersion into my research. I managed to jot down my thoughts and observations whenever I got the chance. This type of informal participant observation was very commonplace. I kept notes of important points on my iphone with an app called SimpleNote. These notes contributed to my field notes and journal entries. Within SimpleNote I have also kept a running list of news articles and documents revolving around topics of Muslims and mental health that were forwarded to me by community members or shared publicly on social media.*
>
> *The notes and entries I collected helped inform me as to what common themes might arise from my research questions. For that reason my field notes, my personal journal, my academic journal became very intertwined. Learning to distinguish one piece from another has proved to be a very difficult task. The most difficult part is the disabling factor of not being able to speak to my friends and family about my research, for fear of violating confidentiality. I believe this precaution has stemmed over very heavily into my personal life, being very aware of what I am saying and how I am saying it. Yet, it has been a very important learning point for me to realize that voicing my opinions and standing up for others, and myself is important. There are nuanced ways to do this that do not reveal anyone's identity or experiences directly but allow others to learn the powerful lessons. This is what I am currently piecing together with my data analysis.*
>
> *Participant observation has allowed me to feel confident in conducting my formal analyses. There was verbal support from my community, and many of my friends stated that they were in fact excited and thankful that I was delving into this hidden topic. There came to be a whispered common consensus that emotional health is a very touchy and problematic topic within our community, but now it is due time to address the issues.*
>
> *The parallels between my own experience and that of my participants are strikingly similar. I have been forced to recognize the enormity of this work.*

Many days I have felt as if I am drowning in this hub of information and stories- this collective feeling of helplessness and frustration. Frustration with the issues, frustration with the lack of support, frustration of fear of voicing our opinions, frustration of fear of acknowledgment of these issues from the ones we call our own.

When I hear particular narratives from the American Muslim community at large, I can't help but relate it directly to my own research.

I feel like I am consumed in it.

I feel like in this way I have been unable to fully reach out to my academic colleagues for in-depth guidance.

I want to be able to speak about these things with those that are a part of the Muslim community, who understand the nuances this research entails without me having to point it out.

I am my research participant."

(Journal Entry: Summer 2015)

The part of summer 2015 that was not spent listening was spent transcribing and coding, reviewing background literature, and researching theoretical frameworks applicable to my data. The former resulted in reviewing over 200 articles in some context that were entered into my Zotero database. And the latter contributed to developing framing analysis, using modified grounded theory analysis, and NVivo qualitative data analysis software to identify key themes and inform the interpretation of findings. With the help of Excel, I worked on generating descriptive statistics of the quantitative surveys and self-reported health histories, to contextualize the qualitative findings. By summer of 2016 I had transcribed all of my interviews and was deep into the process of thematic analysis. And then all of my work was lost.

After the summer of 2015 had gone smoothly, the summer of 2016 turned into a

complete nightmare. My personal computer held all of the research information, stored properly- in only one place- according to all research protocols set by the Boston University School of Medicine Institutional Review Board. On a hot summer day, nearing the end of Ramadan, my computer crashed, and nearly all of my data was wiped. The few pieces I salvaged were snippets of interview clips that were still stored on my phone, which had been used for recording. There were also handwritten notes I had taken throughout my fieldwork, during and after my interviews, and while working on analysis I kept a few journal entries like the one below:

> *With qualitative research I am trying to understand people (Muslim Americans and how they make sense of emotional wellbeing), context (the factors that influence mental health), and the interaction between the two.*
>
> *The data I have collected falls into two categories: structured text (books, journal articles, news articles, and surveys) and unstructured text (conversations and transcribed interviews). My qualitative data analysis aims to take the collected data and draw out patterns from the concepts and insights arising from my participants' views and experiences.*
>
> *Since I, the researcher, am the primary tool, I have tried to be as flexible and reflexive as possible throughout the process. My auto-ethnographic elements facilitate the way in which I analyze my data that consists of my participant's opinions, values, and behaviors- making it nearly impossible to reduce the data to numbers. Still only using the quantitative surveys for self-reported health histories with Excel to determine specific characteristics of demographics and medical histories. Would make life a lot easier if you could do it for life histories, but guess that's why people, and anthropologists, will always be relevant.*
>
> *I am still planning on taking a phenomenological and modified grounded theory approach to data analysis. While I plan to later analyze the transcripts using a modified grounded theory approach, with NVivo, I am first identifying key themes by triangulation of content, narrative, and discourse analysis. With content analysis I am able to categorize verbal and behavioral data on two levels: descriptive (What is the data) and interpretive (What is meant by the data), this is particularly important in conjunction with the self-reported surveys where participants might not mark off any categories under the psychiatric symptoms but will bring them up during the interviews.*

Narrative data analysis then allows me to focus on my participants' stories as told through their own words, validating their stories.

Again, my own positionality is important to note when it comes to reformulating their stories. Since this is linguistically subjective, discourse analysis helps add another layer of validity. Using discourse analysis, I am able to take the actual transcriptions (the literal spoken word) and further expand on what was expressed.

Whether my participants expressed themselves through straightforward terms or if they were more vague and indirect in the ways that they communicated. For example, it is helpful to differentiate when my participants use explicit "I" statements or implicit "we, us" statements when referring to their experiences as an American Muslim. I believe triangulation of these methods of analyses, along with reference to the context they are interpreting, is crucial to accurately portray the explanations of my findings.

Discourse analysis has definitely been one of the most useful methods to help start the analyzing of my data. It allows for there to be a focus on less of what is said and more on how it is said. In developing my code book my first approach was to divide statements between explicit ("I" statements) and implicit (We, us them, etc. statements).

I understand the ethical concerns present when interpreting another's words. To avoid and limit misconstruing statements, I asked for clarification during interviews and many times respondents would say "you understand" at the end of a statement. So I feel more comfortable with discourse analysis.

It seemed many of my participants were highly aware that I would be performing some type of discourse analysis. That someone will be reviewing their statements and they will be subjected to another's eye.

Because of this I feel there was an even stronger emphasis and discourse around community. Many participants noted how important community was for them in order to build a support system, even if support came in ways that weren't directly targeted towards improving emotional wellbeing.

Note: "Development of concepts which help us to understand social phenomena in natural (rather than experimental) settings, giving due emphasis to the meanings, experiences and views of the participants." (Pope and Mays 1995)

(Journal Entry: Summer 2015)

Following the chaotic mishap, I reached out to my participants to conduct follow-up interviews. I spent six months from July 2016 to December 2016 working as quickly as possible to recover much of my work that had been wiped away in a single moment. And once I accepted that I could not remain in purgatory forever, I finally delved into the writing process.

Writing an Analysis

As I began the process of translating my research into a final composition, it became very important for me to think about *how* to write and discuss my participants and their experiences in the most effective and applicable manner. As I recalled my participants' stories in my mind and on paper, I did so using only their given pseudonyms and not their real names, utilizing cognitive distancing as a protective measure to delve further into analysis.

Working with and studying vulnerable populations, who in this day and age, are doubly stigmatized- once for experiencing mental illness, and second for being Muslim was a difficult and draining process. As someone who has experienced different types of mental distress and fits the category of Muslim, for me self-reflection and positionality were important learned processes for understanding my own experiences in relation to my research. I have taken precautions to write in a way that does not dehumanize any one particular individual or system but constructs and critiques a multidimensional portrait of the various factors arising from power imbalances such as structural institutions, broad culture and religious norms, and political rhetoric that contribute to unique challenges for

Muslim Americans. My tone and outlook aim to be neutral with critical discourse; I do not believe I can write a piece about my own experiences and the experiences of a community I belong to with an absolute value of neutrality- nor is that the aim of this project. I believe constructive criticism is applicable and necessary.

To preparing for writing ethnography, I began by studying and interpreting ethnographies with particular focus to related subject matter and an author's use of style and voice. As I worked through the texts of various ethnographers, I learned to recognize and be attentive towards various methodologies for writing about particular subjects. In particular I learned to pay heed to the ways in which authors articulated their thoughts and findings with stigmatized populations.

Four such texts aimed to unearth the lived experiences of vulnerable populations, that heavily influenced my own work: Phillippe Bourgois & Jeff Schonberg's *Righteous Dopefiend* (2009), Merrill Singer's *The Face of Social Suffering: The Life History of a Drug Addict* (2006), Emily Mendenhall's *Syndemic Suffering: Social Distress, Depression, and Diabetes among Mexican Immigrant Women* (2016), and *Patients and Agents: Mental Illness, Modernity, and Islam in Sylhet, Bangladesh* by Alyson Callan (2012).

These ethnographies revealed different stylistic approaches and key techniques for conveying the histories and lives of "hidden", or perhaps more accurately stated as "less acknowledged" populations. Through use of various strategies each of the aforementioned authors brought to light stigmatized populations, be it those experiencing homelessness, drug addiction, mental illness, or another endemic- together participants

and authors revealed much through their interactions with one another. While I pondered the guiding factors of my research- I repeatedly reflected upon the experiences that pushed me to delve into this research, experiences that challenged me to address my own biases and broaden my world views and understanding about even the most stigmatized of topics.

As an anthropologist I find it vital that my work be tailored to my audience, in terms of readability and language, while still doing justice to the meanings of the narratives of my participants and to the field of anthropology. With a focus on style, and its application in uncovering analysis, the next three chapters weave analysis within narrative, allowing key themes to slowly rise up and out of the well. In particular I borrowed from the style of Mendenhall. I used part of my own experiences, pieces of autoethnography, as a practice exercise to discuss ethnographic experiences through narrative and discourse analysis, translated in a similar style to Mendenhall's work. This particular style takes each participant into account and separately categorizes each individual's experience; first providing a background on the individual, describing the setting where the interview took place, and then including key excerpts of the participant's narrative.

CHAPTER 4

"COMPLETELY MENTAL!"

To understand my participants perceptions around mental health, I sought first to gain a comprehensive understanding of when and how they formed their understanding of the world. I took a step back and aimed to identify critical experiences that influenced my participants' conceptualization of mental health.

As expected, the critical experiences that influence one's perceptions and beliefs are vast. To make sense of these experiences, to process them in a more digestible way, I categorized them using developmental psychologists Baltes, Reese, and Lipsitt's (1980) theory that the dynamic & reciprocal interaction of the individual and a proposed context is impacted by three major types of influences: normative age-graded influences, normative history-graded influences, and non-normative life event influences.

In this chapter, I utilize the first of these categories, normative age-graded influences, to begin the process of understanding my participants' experiences in the proposed context of mental health. I employ explanatory model and phenomenological approaches to investigate when and how stigma is learned and the role biomedicalization plays in how Muslim-Americans understand and define mental/emotional health.

"Your" story begins, before You

On what I had hoped would be a lazy Friday afternoon, I reluctantly pulled myself out of bed, put on my sneakers, and headed south of my apartment. In the sweltering heat, I walked ten and a quarter blocks to meet Laila. I know it was exactly 10.25 blocks,

because I am the kind of person who considers the walk to the gym to be a workout in and of itself. As I reached the squash courts where we had agreed to meet, I saw Laila on the ground with both legs stretched out in front of her, leaning forward with her arms and touching her toes. Today her long black hair was pulled back tightly in a long and bouncy ponytail, with side bangs, now sweaty, stuck to her forehead, yet her face was glowing with excitement. I rolled my eyes at how a person so drenched in sweat could look so happy; I was still groaning to myself about having to leave my air-conditioned apartment, walk through the blistering sun, only to meet someone in a gym court. Sigh. The things we do for research.

As Laila looked up and saw me walking towards her, she immediately jumped up, tied her hot PINK sweatshirt around her waist, and shouted, “Hold yer horses, she’s about to blow!” Before I could speak, I smelt what she was referring to and we proceeded to explode into a fit of giggles. (Readers, I am sorry to disappoint you so early on that the only thing these two brown women were blowing up was plain old flatulence.) Eventually, we were able to gather our wits, and begin a normal conversation.

We began our interview sprawled out in the corner of the gym floor as I asked Laila to tell me her story:

> *“I’m Libyan. Well, I was born here but my parents are from Libya. My dad came here (to America) after getting his bachelor's and wanted to get his master's so he moved to the South. The more his brothers pushed him to come back (to Libya) the less he wanted to (go back).*
>
> *Then finally he was like “OK well if I have to go back I want to see NYC before I leave…..so he and his friends went to NYC and he ended up just like staying there and living there and he never went back because he really liked America. Well, he only went back to marry my mom and bring her back too, so that’s how I came to be.”*

Laila's response, in being asked about her story, started with her parents' story. When I met my second participant, a similar interaction took place.

Unlike Laila, I had never met Ibrahim before- and when we did meet, I was a bit intimidated. He was a large, beefy man towering well over 6 feet with a short neck and a very dark, well-trimmed beard. His large, big-boned structure, supplemented with a very formal external demeanor, certainly did not put me at ease. He showed up for our "interview" at a coffee house, on a Saturday morning in 95°F weather, dressed in a rigid navy suit, white dress shirt, and striped light blue tie complete with a sleek brown belt and polished brown shoes. The day of our initial meeting he did not seem to be the "Hagrid[7] 2.0" who I see him as now, but as a giant who spent time his days in the modern-day Azkaban[8] aka the corporate world.

Nevertheless, I tried to put these petrifying thoughts behind me and began the interview with a very original question "Tell me about yourself". As soon as he spoke, all the internal judgements I had formed in the first few seconds of meeting him quickly fizzled away.

In an eager and excited tone, he began:

> *"I was born and raised in a small town in Alabama. My grandparents moved there from Iran in the 1960s to teach. It was a really small town, surrounded by a lot of rural area, and a lot of people had never seen a person from the Middle East. When they moved there, people would take pictures of them at supermarket.*
>
> *By the time my parents were there it had become a bit more multicultural, but my parents worked in more rural parts. For them education was everything. They*

---

[7] Hagrid- is a character from J.K. Rowling's Harry Potter series who is half giant and a very kind man.

[8] Azkaban- a prison in the Harry Potter saga.

were education obsessed, my parents were really proud of education achievements over any other kind of achievements. Because of that I learned to be competitive academically. I would describe myself as a leftist, an idealist, I'm passionate about human rights, I used to be President of an Amnesty International Chapter."

While I was surprised by Ibrahim's chatty nature, I was not too surprised that, similar to Laila's introduction, Ibrahim's synopsis of himself included his parents' story, and also his grandparents and their story. I eagerly waited to see if this trend would continue on as I met with my other participants - sure enough, it did.

On Sunday, I met Noora inside of a shopping mall food-court. Despite her short and delicate frame, Noora stood out like a royal queen; today her blonde & brown ombre-styled hair was perfectly blow dried and coiffured with a pearl headband perched atop. As I approached her, she stood up from her seat and gave me a hug. After a few minutes of chit-chat, we walked over to the Dairy Queen to treat ourselves to some Blizzards. When we returned to our table and sat down, I watched as Noora carefully scooped out her vanilla ice cream, one spoonful at a time. I, on the other hand, was watching carefully because I had sadly devoured mine in just five bites. Noticing this, Noora quickly offered me some of hers.

As I would come to know her, Noora was a very gentle and compassionate soul. She tended to tread cautiously in all endeavors and within minutes of our interview her sensitivity towards others became obvious. When I asked Noora to tell me her story, like Laila and Ibrahim, she too began with her family:

"My parents are from Malaysia and our family lived there when I was younger for a few years. I was born in the United States but we moved back there (Malaysia) and then came back here. We settled down in a small town in New England. There are a lot of us (siblings) so my parents had to sacrifice a lot."

Over the weeks to come, I would meet another seven participants: Raheem, Mustafa, Maria, Yasmin, Niyaz, Laiq, and Bisma, and like the three we will focus on in this chapter, they began their own stories by including their family's stories. As I was interviewing participants, I thought about how I would answer my own "tell me about your story" question, and I realized that I too would provide a response that included my family history. Although Laila's parents were Libyan, Ibrahim's Persian, Noora's Malaysian, and mine Pakistani- we all shared a similar set of experiences. The views of our parents- shaped by their past, their roots and histories have now shaped our present. Although we represented various diasporas, we all shared the experiences of being children of immigrants, and we all hope to achieve the American Dream.

Thus, for my participants, being the children of immigrants, is a shared subculture and their family's history of immigration becomes a normative environmental determinant. This determinant, of being the children of immigrants, can be used as a normative age-graded factor in analyzing the participants' viewpoints. Normative age-graded influences are those influences, either biological or environmental (which include family life-cycle, educational, and occupational influences), within the life course that are correlated with chronological age. Each culture and/or subculture has its own set of age-graded normative influences. For my participants the normative age-graded environmental determinant of being the child of immigrants becomes more than a box they check off when applying to college. It is a narrative anchor, an identity marker that allows them to form positionality that is mutually shared; their cross-cultural positionality impacts the discourse around mental health they will and will not take part in.

As a society we navigate shared social and cultural spaces, our lives are both individual and collective, and what we learn about the world happens in some form of collaboration with others and informs our positionality. Positionality, as described by Alcoff (1988) challenges the notion that identity is fixed and instead suggests that individuals occupy multiple identities which are fluid and dialogical, contextually situated, and constantly amended and reproduced. Our identities and lived experiences are the ways in which we engage and interact with the world, they inform our positions- they inform how we take meaning.

Creating meaning is a fundamental social process; it is a phenomenon that affects what we see as the perceived reality of ourselves and of various collective groups. As Foucault is quoted in *Truth: Engagements Across Philosophical Traditions* (Medina and Wood 2008) “in every society the production of discourse is at once controlled, selected, organized and redistributed according to a certain number of procedures...” (p. 216), and then continues in *The Birth of Biopolitics: Lectures au Collège de France* (Foucault, Senellart, and Burchell 2008) stating that individuals placed into different boxed categories and subcategories of being that subject them to different forms of social inclusion/exclusion - coining this set of procedures as ‘biopolitics’ (or the administrative management of life). He further theorized that the inclusion/exclusion continues to occur as hierarchies of privilege and marginalization continue to be reproduced- shaping individuals’ experiences and positions in the world. Thus, for my participants those attributes lower in the current socio-political hierarchy, such as being the children of Muslim immigrants, shape their perspectives of themselves. In turn this shapes the ways

in which they understand themselves as individuals, how they perceive others, and their positionality as social participants and agents, meaning how they interact with others.

My participants' existence between various positionalities was of significant interest to me in understanding the tensions surrounding mental health discourses. I aimed to learn and understand the ways in which their positionality developed: what role did their unique cross-cultural upbringing play in their perceptions and attitudes towards mental health, when did they learn that mental health was a stigmatized subject, and why do they think it continues to be a stigmatized topic?

Mental: Do NOT Enter The Conversation

> *The Greeks, who were apparently strong on visual aids, originated the term stigma to refer to bodily sins designed to expose something unusual and bad about the moral status of the signifier.*
>
> *The signs were cut or burnt into the body and advertised that the bearer was a slave, a criminal, or a traitor—a blemished person, ritually polluted, to be avoided, especially in public places.* (Goffman 1963)

To understand when my participants learned about mental health, I asked them about discussions regarding mental health they had with their parents. Laila, who was by no means a quiet personality, became rigid and ambivalent when I asked her to describe her what she had learned about mental health from her parents. In the span of one short sentence, her tone went from hesitant to slightly angry, replying:

> "*They do not discuss mental health because they don't believe in it."*

Then sweeping her hair out of her eyes, she continued with more vigor in her voice:

> *"They think it's all in your mind. They think that you just kind of have to snap out of it.*

They think that you're just being dramatic."

Her voice now continuing to rise, she imitated her mother, with a scowl on her face and her pointing at me repeatedly with her entire hand, palm-up, stretching out in front of her:

> *"You're depressed? Why are you sad? For what reason on God's earth do you have to be sad? Don't be sad."*

After a few moments, Laila let out a sigh of exasperation and now, bring her hands down to her

side, no longer imitating her mother, went on:

> *"They think it's an easy fix. And that it's just. And if you didn't "fix it" then you're being lazy and trying to blame it on something."*

After this Laila crossed her arms and we sat silently for a few moments. Slowly she uncrossed her arms and while she looked down and started picking at the frayed sleeves of her PINK sweatshirt she spoke:

> *"There's partially a lack of awareness, a lack of knowledge, so they don't talk about it.*
> *But even when they do learn about it, they don't really understand because they just don't value feelings, they value hard work. If you're feeling sad about something, they think you are just ungrateful and instead of being sad you need to fix whatever it is that is making you sad. They remind you that they came to the country with $20 and the clothes on their back and they didn't have everything they wanted, but that didn't make them sad. They just kept working, they didn't have time to be sad. It's frustrating because like I said, because besides "fix-it" no other option can exist for them. I get it though, and I wish I could believe it because if I could just fix-it, then why wouldn't I?"*

Laila, who was normally very energetic and upbeat was quite upset during this part of the session. She was frustrated with her parents' views regarding the subject and yet she also understood why her parents held their particular views, showcasing her own ability to incorporate and understand various explanatory models of mental health.

Kleinman's theory of explanatory models (EMs) showcases that individuals and groups can have vastly different notions of health and disease. EMs are "notions about an episode of sickness and its treatment that are employed by those engaged in the clinical process" (Kleinman 1981, 105). Eliciting EMs allows us to acknowledge the beliefs individuals hold regarding mental health, and to delve into the personal and social meanings attached to mental health. Individuals may have different explanatory models, which are influenced by their social and cultural contexts and prior experiences. Thus, although Laila's EMs are influenced by the mainstream American biopsychosocial model, the emphasis on which aspects are most important may vary between her and another individual (like her mother), who does not share an interstitial identity similar to her own.

Understanding EMs helps to clarify conflicts not related to simply to different levels of knowledge, but to different values. Within a short discourse it becomes apparent that Laila grapples and negotiates between two different explanatory models. Laila's parents' story is part of her story, their values are part of hers. Laila is able to place herself in her parents' views and also expand upon them allowing EMs to emerge in the midst of the stories that showcase this phenomenon. A combination Laila's family's story, her own story, and her ability to engage in reflective analysis, showcases an understanding of the types of explanatory models she employs, the views that influence her own receptivity to mental health messaging and behaviors.

Similarly, as Ibrahim and I delved into about his conversations around mental health with his parents, his previously excited and eager tone now faded away. As he

refused to make eye contact, he instead began to ceaselessly smooth out non-existent wrinkles on his perfectly starched jacket. After some time, he spoke:

> *"I didn't grow up in the best of households. To the outside world we looked like the*
> *perfect family. Mom, Dad, and two kids. Both my parents were doctors, both very well-respected in the community. But my dad, he wasn't all there. Still isn't."*

I wanted to understand what he meant but was also cognizant of pushing him towards revealing any information that he did not want me to share. I waited a few moments to see if he would continue, and my surprise- he did:

> *"My dad always seemed unhappy. He was prone to fits of shouting and sullen moods where he retreated from us (the family). Some very minor thing, leaving your bag on the floor, or something else that would just irritate a normal person- it would have him in a raging fury. Screaming at us and telling us how we were useless and incapable. After he calmed down, then he would apologize. It was always very confusing.'*

I asked Ibrahim to tell me a bit more about what was confusing.

> *"I just didn't understand why he would do it, apologize and say he wouldn't do it, and then keep doing it. It was a vicious cycle, and we never talked about it. In Persian communities you tell everyone everything. People brag about the smallest, most insignificant things. "Oh, my husband, he can iron his own clothes. Oh, my daughter, she makes her own bed." Really, the smallest stupidest things, they will boast about.*
>
> *So, if it's not something you want to let the entire world know about, if it's something you know you want to hide from everyone- that's how you know it must be really, really bad. Even the kids know you never talk about it."*

He continued:

> *"I didn't know that he had anger issues or struggled with depression. I found out that's what it was much later on in life. That's when he found out too. He didn't know either."*

Like Laila, Ibrahim also shifted responsibility of understanding mental health on and then off of his parents. His experiences showcasing a conflicted "habitus." In Samuelson & Steffan's (2004) article, Bourdieu's concept of habitus "designates a set of generative and durable dispositions acquired through socialization", in laymen terms- habitus are the set of values, perceptions, and attitudes we acquire through socialization. In line with normative age-graded influences, early childhood experiences carry a "disproportionate weight" in the development of habitus which is acquired unconsciously (Bourdieu 1977, 78). For my participants, like Laila and Ibrahim, habitus is informed by two opposing spheres of influences: that of mainstream American culture which allows for at least a partial discussion of mental health and that of their homes, where the topic was closed for discussion. These opposing views result in a polarized habitus, leaving my participants ambivalent in engaging with the topic of mental health.

Discussing Mental Health: *Highly Polarized*

As Ibrahim mentioned, "If it's not something you want to let the entire world know about, if it's something you know you want to hide from everyone- that's how you

know it must be really, really bad. Even the kids know you never talk about it."

Continuing on this topic, was Noora, as I asked her about the discussions she had with her parents regarding mental health, she spoke about the discussions they did not have:

> *"We never talk about it even though the problem lives in our house. My brother is not a problem but his illness is the problem we don't talk about. He screams, he throws things, he loses it from time to time. We can't always go to public places because we don't know how he will be that day. But we love him and that's never going to change. But my parents think if they put a name to it (disease), then we will all be marked for life"*

As Noora and I continued to speak she never disclosed what type of illness her brother was battling, instead she quickly transitioned into sharing her best friend's experiences:

> *"Her brother committed suicide. That's what it was but no one said it. In the mosque they just didn't say anything about how the death happened. The Imam told us to just pray that his sins be forgiven.*
>
> *It's an unspoken thing in our friendship. We both know what the other has gone through, we have been inside the other's home for many years, but we never say it to each other."*

As Noora noted that "if they put a name to it, then we all (her family) would be marked for life" and alluded to the fact that mental illness was so stigmatized that it could not be discussed even after one's death brought to light just how stigmatized the topic was for my participants and their loved ones. Both Noora and her friend, both aimed to deflect any detection of the "mark" that could be brought upon themselves due to their brothers' illnesses. Similarly, in Ibrahim's case his family was unwilling to discuss the issues related to his father for fear that anyone outside the home would know what took place inside. Although they were afraid of their loved ones being stigmatized, were they

also afraid they too would be stigmatized even though they did not directly belong to the "mentally ill" group?

In sociologist Erving Goffman's book *Stigma: Notes on the Management of Spoiled Identity* (Goffman 1963), he defines stigma as "the situation of the individual who is disqualified from full social acceptance" due to "the dynamics of shameful differentness", categorizing stigma as a social construction that involves two fundamental components: the recognition of difference based on some distinguishing characteristic—a "mark," and a consequent devaluation of that person. He goes on to describes how one can feel stigmatized by belonging to a particular group, such as "the mentally ill" who are devalued in particular social contexts and are regarded as flawed due to the presence of their mark of being "mentally ill". Those who belong to the stigmatized group feel shame due to their mark which prevents them from meeting society's standards. For fear of being discredited, the stigmatized learn to conceal their "mark" in order to manage other impressions of themselves.

The original ethnographic descriptions put forth by Goffman on *how* stigma processes occur have been expanded upon, by various disciplines, to show *why* stigmatization occurs. Evolutionary psychologists like Kurzban and Leary (2001) suggest that stigma is a byproduct of normal behavior and social cognition; humans have evolved to function in groups and groups have learned to detect members that "risk impeding the group's functioning", thus creating humans' collective capacity to stigmatize.

Griffith and Kohrt's (2016) present a social neuroscience perspective for understanding stigma, stating that "stigma is a normal function of normal brains resulting

from evolutionary processes in human group behavior". Their description of stigma as an affliction of normal people and normal brains serves not to ascribe stigma with either a positive or negative connotation, but simply serves as an explanation as to why stigma exists in society. They state, "detecting a mark of stigma -appears to generate conflict between incoming sociobiological information and an expected reality" and note five primary types of stigma: Peril stigma, Moral stigma, Disruption stigma, Courtesy stigma, and Empathy Fatigue.

When Ibrahim discusses his father's shouting and mood swings as a 'vicious cycle", and Noora mentioning her brother's screaming, throwing things, and "losing it", they are alluding to the first of these stigmas, peril stigma. This is the type of stigma which triggers perceptions of potential danger; when an individual with mental illness shows odd, impulsive, or unpredictable behaviors- others begin to fear that they are in real danger.

As Laila discloses her own struggles with mental illness and her parent's demands that she just "fix it", she is bringing to light moral stigma. This is the type of stigma that arises when a person is perceived as a threat for challenging the beliefs and values of the primary group they belong to. An individual's symptoms of mental illness, (such as apathy of depression, behavioral avoidance of anxiety disorders, or symptoms of psychosis) may trigger moral stigma when their symptoms are instead interpreted by others as voluntary choices rather than involuntary effects of their mental afflictions (ex: laziness instead of symptomatic apathy , unwillingness to accept personal responsibility

for one's life instead of anxiety, or lack of adhering to social protocols instead of the symptoms of psychosis) Moral stigma will be discussed further in Chapter 6.

Noora's discourse regarding her brother's illness "We can't always go to public places because we don't know how he will be that day" showcases how her and her families' activities become limited due to the nature of her brother's symptoms. This brings to light the third stigma, disruption stigma, which is when an individual's behaviors or symptoms are experienced as interfering with functioning of their family or another group to which they belong. Disruption stigma is evoked when interacting with those with disabilities because the caretaker's professional and social obligations are impacted by having to tend to someone else's needs.

As Noora goes on to explicitly state that her entire family would be "marked" if they verbalized her brother's afflictions- she is afraid of being stigmatized herself. The fourth type of stigma, courtesy stigma, is that stigma which is an association with "the marked" that results in loss of social status. This type of stigma typically becomes extended to those in close physical proximity to a stigmatized individual(s), as if they were acquiring a "courtesy membership" in the stigmatized group; family members or mental health professionals are vulnerable to courtesy stigma by their associations with individuals with mental illness.

The fifth and final type of stigma noted by Griffith and Kohrt is empathy fatigue. Empathy fatigue, collectively represents when "family members, friends, and co-workers feel too distressed to engage in close proximity with persons in suffering, i.e., a feeling that it is "too much emotional work." Mental illnesses associated with feelings of severe

depression, anxiety, and chronic pain may evoke empathy fatigue." The result being avoidance or high levels of social distance from the persons in suffering. As I went through this journey of meeting with individuals and learning their stories, many of my participant's opened up about their experiences for the first time. Having found their first source (myself) that was confined to the confidentiality principles of the Institutional Review Board, my participants continued reaching out to me to discuss their feelings, well after the initial interviews. As I consistently tried to re-direct them to "proper" resources (to no avail), what resulted was empathy fatigue on my end. I had to take several months before I could re-engage with the work without feeling completely consumed by my participants and their stories.

The five types of stigmas mentioned are merely a start of the types of external stigmas that impact the lives of my participants and their loved ones. Perhaps the most dangerous type of stigma is these external stigmas leading to internalized stigma. Internalized stigma results when various other types of stigmas, be it peril, moral, or another- those stigmas provide a less than favorable lens for individuals to perceive themselves. Individuals begin to judge their own experiences in rather contemptuous and dismissive manners, and the results can impact one's sense of self and being. Recent innovations in brain imaging physically show how our brains engage in stigmatizing, via dual social cognition systems: "one for rapid, categorical, group member-to-group member relatedness and another for slower, individualized, person-to-person-relatedness" that they utilize biologically to stream information (Beer and Ochsner 2006). With a background in both the natural and social sciences, I struggle with my own approach and

positionality in describing complex phenomenon such as stigma; while I believe it is important to note the biological basis for stigma, it is equally important to understand its resulting implications. Perhaps then, while the rapid group member-to-group member processes cause us to stigmatize others, the slower person-to-person processes can provide us an avenue to disrupt and re-evaluate the harmful implications that have real impacts on those dealing with mental illness and related issues.

The Perils of Biomedicalization

Mental according to Merriam Webster Dictionary

(1): of, relating to, or affected by a psychiatric disorder

(2): mentally disordered: MAD, CRAZY

Synonyms: insane, deranged, demented, lunatic, unhinged

As I continued the discussion around mental health with Laila and others, our conversations centering around how they learned about mental health and the stigmas and taboos surrounding it- our conversations evolved from what they learned, said or unsaid, in their households and from their parents and family members, but also what they continued to learn from society at-large about mental/emotional health. Previously discussed in the Methods Chapter, "emotional health" served as an in vivo code- a more culturally accessible term- that allowed for open and honest discourse, centered around issues related to mental health, to take place. With my initial questions regarding emotional vs. mental, I had anticipated there would be some differences in how participants viewed the two terminologies, but I was surprised by the vast extent of differences evoked by responses to each term. This section discusses the ways in which

participants personally defined and differentiated between emotional health and mental health and how the defining and understanding of these terms shaped and contributed to their perspectives of mental health.

When I asked Laila for her definitions of emotional and then mental health, she stated a few times that she felt unqualified to give an answer; with my prompting that this was not a test on which she would be graded, nor would her real identity[9] ever be revealed, she provided the following response:

> *"Emotional health focuses on how we are feeling, our shifts in mood, and how certain things in life can affect that. For example, it would look at how an abusive relationship is making someone more depressed and drained. It doesn't focus on the physical aspects, but more the emotional drain a disease or situation has on a person.*
>
> *Emotional health is something that I think everyone kind of looks at because it is something that happens to all of us, everyone can relate to it.*
>
> *Mental health is about your psychological state- it begins to delve into our physical state."*

I was intrigued at the way in which she described mental health as a "state" but as term that was only the "beginning" to "our physical state", and yet when she described emotional health the term evoked much more fluidity. Her definition of emotional health incorporated and referred to everyday living, having the ability to understand and navigate emotions each day- setting a positive framework around emotional health. This is in contrast to her definition of mental health which is short and rigid, referring to a "state", i.e. a psychological state which aids into the creation of a physical state.

[9] Reminder that all names are pseudonyms

While Laila was reserved in her definitions regarding mental health, Raheem, a loud and out-spoken Lebanese man, was certainly not. When Raheem and I originally agreed to meet for the interview I had suggested that we meet in a private area, perhaps in a school meeting room but instead Raheem suggested meeting at a pizza shop. Near Harvard Square, we grabbed a few slices of pizza and then headed to the very opposite of a meeting room- a large and open park. Perhaps that is the best example of who Raheem is- always open, cheery, and with lots of life to share. With short curly hair and a never disappearing five o'clock shadow- Raheem was always to be found with a smile on his face and his bright hazel eyes constantly darting around. As we approached a nearby bench, Raheem sat down cross-legged, grabbed a slice of pizza and said "Ok, let's go!" As I would get to know him, he was always delightfulness, a little reckless, impatient, and loud but never failed to bring a little piece of sunniness to any crowd.

As I asked Raheem to describe emotional health, it seemed he had already spent quite some time considering the topic, as he had much to say:

> *"Emotional health looks like, its defined by honesty with oneself. Its defined by comfort with discomfort. Its defined by self-reflection, self-examination. It's being okay with internal silence. Sometimes seeking internal silence. Its defined by being confident in one's feelings, which entails feeling one's feelings, and being confident in them, being able to stay clear of toxicity. It's a lens of self-perception.'*
>
> *Emotional health means getting help sorting all these things out when you are unable to do that, which I think requires knowing you are unable to do that. I guess that's a lot to ask of people but yea, I guess that's because we don't live in an emotionally healthy society. In an objective sense it's not that high of a standard. But given where we are it seems like a high standard, but it's really not. That's my comprehensive answer."*

In contract, Raheem's definition of mental health looked starkly different:

> *"Mental health, it's a clinical term. It suffices but its hard to get someone to acknowledge when they are going through a tough time, its hard to tell them 'hey you are mentally unhealthy, or do you have a mental health issue'. I mean that's true, they are not as well as they could be but there's always the stigma, like what do you even say? Mental health issues? Mentally unwell?*

Continuing:

> *"Mental Health" (making quotation marks with hands)……. Ooooo it's a scary term (flailing his arms in the air and then bringing them back down) Like when you say mental health it just resonates with a diagnosis like bipolar, schizophrenic, etc. Like the conversation around guns and those with mental illness shouldn't have access to guns. We are always talking about those who are diagnosed with really severe and really destructive diseases.*
>
> *But when we speak of mental health though we aren't always talking about people who are in danger in hurting themselves or hurting others, a lot of times we are just talking about just people who are sad or hurting a lot. I don't know where to make the delineation though, I don't know if I'm qualified to say when you cross the line into "more severe".*
>
> *You don't need to be diagnosed to recognize you don't know what's going on in your basement. Your basement is the foundation on which you build your life and if your basement is shaky, then everything else will be too. We don't need to use the language of medicalization, the language of medicine, the language of treatment, the language of drug to talk about what is going on in the basement. I mean obviously antidepressants can help people, some people need that in order to be comfortable going into their basement. In that case, absolutely medicine has helped. But my conversations with my therapist have been about spirituality, about purpose. I'm not being treated as a medical disorder, he's not a medical doctor, he's someone who knows how people work, what moves people. For me, mental health and self-knowledge are intricately tied together."*

He then continues, bringing together both emotional and mental health:

"I think emotional health encompasses mental health and more. It is the right terminology when we are speaking about managing our burdens. We are speaking of motivation. We are speaking of purpose. We are speaking of life unloved. I don't know what that says about mental health vs emotional health, but I think that its important that we acknowledge every single person carries trauma and pressure and burden- mental and emotional burden.

As Raheem discusses emotional versus mental health there is a stark difference that one's emotional health is evaluated by the individual, by evaluating their own "internal" processes, while mental health is that evaluation conducted by someone other than yourself. Similar to Laila's fluid definition of emotional health, Raheem mentions that emotional health requires one's own "self-reflection, self-examination" and requires a "lens" facing inward, which is in contrast with how he perceives mental health to be. Raheem argues that mental health is a "clinical term" and that "we don't need to use the language of medicalization, the language of medicine, the language of treatment, the language of drugs" and states that "emotional health encompasses mental health and more" meaning that mental health can be limiting in its approach to "managing our burdens".

Raheem's words echo those of Foucault in that it is dehumanizing to separate one's identity from one's body, limiting our understanding of health. In Foucault's analysis between the state and its population, between power and individual subjects, he describes how medicalization becomes a process where more aspects of human existence, behavior, and body are reframed as medical issues and the power of medicine begins to slide into a wider reach (Foucault, Rabinow, and Rose 2003). Raheem argues that this extension of the medical scope, of medicalization, is unnecessary and unwanted, "I'm not

being treated as a medical disorder, he's not a medical doctor, he's someone who knows how people work, what moves people.". He states "we do not live in an emotionally healthy society" – this can be perceived as another result of biomedicalization - the stigma associated with scientific, clinical terms prevents people from understanding and addressing their needs, which are likely as Foucault argues intertwined and not separate from one's identity. Raheem showcases this by saying, "For me, mental health and self-knowledge are intricately tied together."

Ibrahim had similar sentiments to Raheem's. Although he was quite brief in regard to this part of the discussion he stated:

> "*Emotional health is one's comfort within their own mind. It is one's ability to rationalize experiences and relationships in life, to orient one's self in a rational way, to transcend negativity and defeatism, and to create balance of self, no matter the surrounding. Mental health is just more scientific."*

Again, he echoes the language of Laila and Raheem, with mental health providing a limited definition but emotional health providing a way to look past that- perhaps in psychological terms if mental health applies to nature, to what is scientific, then emotional health can be nurtured, that environment you create in order to restore balance. As I continued the conversations with others it became apparent that structures like biomedicine had become an involuntary become a metonym for evaluating mental health; this closed off other important factors and influences into how mental health is informed and viewed, and thus a relatively new term- like emotional health- provided a less stigmatized and more open avenue to discuss the issues at hand.

Niyaz, who had been involved in mental health spaces and discussion significantly more than my other participants, provided further affirmation to the above

definitions by Provided by Laila, Raheem, and Ibrahim. Unlike the three participants just mentioned, Niyaz was much quieter by nature. I met Niyaz at community event focused on South Asian youth and mental health. He was giving a monologue on stage, in a lavender button-down shirt and khakis that were just a bit above his ankle. Beneath his short, clean-cut hair was a handsome but weary face with kind eyes. Once he finished and everyone was done clapping, I went over and introduced myself and my project. He spoke softly, and his composure immediately reminded me of my late uncle. As I would come to learn more about Niyaz and his experiences, I would realize that much of the ethnographic work I was conducting, he had already conducted through his own lived experiences, and this would be apparent as we delved into the definitions of emotional health- Niyaz provided a lengthy and comprehensive response:

> *"Emotional wellbeing I guess like safety in feeling safe and expressing your real emotions. Having an avenue to express discomfort. It is having is a realistic grasp, having a reality based consciousness on what you are thinking and feeling at any given time, and being centered in reality as to what you actually have control over, what you are beating the shit out of yourself for, for no reason, and this is something I've gotten much better at over the past few years, I've learned how to pause and re-assess stuff before it drives me insane. What are things I actually have the power to change… this is really cheesy, but this prayer…"*
>
> *KH: "Oh, I know that prayer!" (Both laugh)*
>
> *"Yea, I usually don't like buying into the prayers but the Serenity one: God, grant me the serenity to accept the things I cannot change, courage to change the things I can, and wisdom to know the difference….that is the big one. Because for me, it is so easy to get wrapped up in things you have no control over. So understanding when you are feeling something, when you are reacting to something. I guess just being aware when fear is driving your life, as it often is in my case. Emotional wellbeing is something I can see everyone relating to.*

Then continuing the conversation into defining mental health, Niyaz stated:

> *"But mental health is more objective, provides a scientific outlook, with metrics that define what is "mental health". Mental health still has a negative connotation to it, the way people would say mental patient or something. For me mental health still conjures up images of insane asylums from movies and TVs and things like that. There are consequences of using a clinical term like that."*

And then, similar to Raheem, as he brought the concepts of emotional and mental health together:

> *"Maybe emotional is a little bit more accurate, if we want to actually create a positive outlook, and from purely a marketing standpoint, emotional wellbeing is probably easier to sell to people vs mental health, and its something people can identify with more because a lot of people will say 'Oh I don't have any mental health issues." Like who wants to admit that? But emotions- we all have emotions. and we all have trouble regulating them, so emotional health, is an easier framework for people to understand. Mental health practitioners can and should use it (emotional health) as a trojan horse."*

In regards to emotional wellbeing Niyaz discusses the importance of having the ability to recognize emotions, and to recognize where they stem from. Similar to Raheem, he too is placing an emphasis on self-reflection, its implications in evaluating one's emotional health, and how the term emotional wellbeing allows for easier accessibility into discussing difficult topics. Niyaz articulates and that the rigid biomedical interpretations of mental health, the likes of which conjure up images of institutionalized clinical spaces, have historically contributed to the phenomenon of mental health being stigmatized. In order to diffuse some of that stigma he offers the following solution: use

a different framework for thinking about mental health issues, emotional health "as a trojan horse".

Language is powerful and the context and intention of the words we use can have a lasting impact on how we perceive the world around us. Mental health is typically discussed using primarily the language of biomedicine, incorporating typical western diagnostic terms such as clinical and disease, create a difficult rather than a helpful environment to discuss related matters. When mental health is limited to biomedically focused interpretations, that model focuses and limits individuals to their diagnoses and symptoms rather than reminding them they are more than their illness. My participants express frustration with the mainstream American biomedical model of care is offered as the exclusive mode of healing, and instead seek care where the pluralism of biomedical, traditional, cultural, and individualized modes of healing are encouraged to emerge.

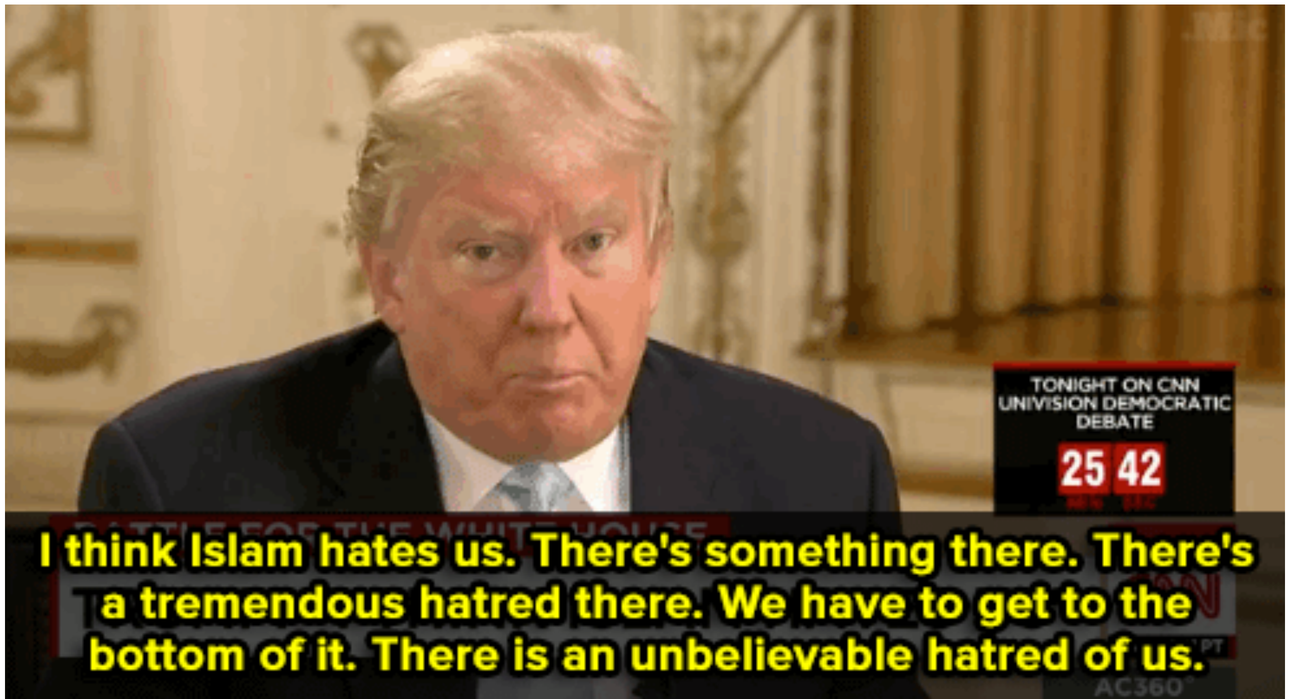
Raheem and Niyaz's statements build upon the argument that the mainstream narrative of care lacks conceptual synchrony between biomedical, social, and cultural models of wellbeing. This is not simply a matter of semantics, the root of the stigma surrounding mental health is shaped by histories, by social norms and conventions, and by our lived experiences. Today, mental health has become a metonym for the structures of biomedicine and its actions- cutting out cultural configurations of one's lived experience, important factors and influences like religion and spirituality, and negating the use of pluralism of thought and resources in healing. In contrast to how mental health was discussed with a need to neatly separate and categorize, conversations around emotional wellbeing placed social processes (like comfort and confidence) alongside

biological processes (like stress and state of mind) opening the door for an ethnomedical approach in mental health. When using the term emotional wellbeing participants put forth the idea that sickness and healing do not operate in a vacuum.

Emotional wellbeing allows for multiple lens to arise, making room for one's perceptions and experiences to take on more positive roles and meaning, and providing us a means to define mental health with a fresh perspective that can incorporate our lived histories and experiences, incorporate multiple explanatory models, and give room to a more positive, less stigmatized framework.

CHAPTER 5

"I THINK ISLAM HATES US"



(CNN 2016)

Tuesday.

9:03 AM.

September 11th, 2001.

It was a pretty ordinary Tuesday morning, except I was more excited than usual because Mrs. King had just slipped me the piece of paper that confirmed I was reading at a 12th grade level; and could finally read Jane Eyre. My cousin who was a few years older than me loved the Bronte sisters and I couldn't wait to read and discuss the same books as her. On the inside I was pretty elated, but you can't go around telling other kids

that in the 6th grade. I was already as nerdy as a sixth-grader could possibly be; with purple “Paddington Bear” glasses I picked out in the fourth grade that were still too big for my face, not to mention my favorite cerulean blue fleece designed for a 71-year-old grandma and not a prepubescent 11-year-old, I already had a hard time trying to fit in. But for the most part this didn’t really bother me because I spent most of my free time obsessing about Harry Potter and other fantasy lands. And now even Jane Eyre was within reach, so I was having a pretty good morning.

I was looking forward to telling my parents that we would be making another library trip that evening. As I was stuffing the newly acquired reading permission slip into my rainbow splattered, Lisa Frank bedazzled folder, our pod’s history teacher came running into our classroom.

“Come and look at the TV right now!” she screamed towards my homeroom teacher.

Mrs. King motioned for us to get up and follow her lead, we raced across the hallway into the other classroom and turned towards the TV.

I didn’t understand what was happening. I saw the Twin Towers. A lot of smoke. Everything just looked chaotic. The news reporters were talking really fast, and even though I read at a 12th grade level I didn’t understand what they were saying. Before I had time to try to piece together what was going on, the history teacher pulled me aside and we stepped out into the hallway.

> *“Some people did something very bad. They crashed planes into buildings, killing a lot of people….. and they looked like you.”*

I stood there quietly, just listening. I still didn't really understand. Something bad happened, I didn't know what happened, but I understood that people got hurt, people got killed. But the next part of her sentence made no sense to me.

> *"They looked like me? Did they also wear Paddington Bear glasses? Were they also really skinny? Were they still trying to lose all their baby teeth?"*

I was confused. But then she continued…

> *"They looked like you. And because of that people are going are going to say things to you. They might say very mean things. And I just want you to be prepared for that."*

Oh.

They were brown.

***

When I started going to preschool, we lived in a neighborhood with plenty of other black and brown kids. We ran around the playgrounds with all types of braids and oils in our hair, bouncing around without anything to fear, except for maybe going too high on the swings. The aromas of our homecooked lunches filled our preschool cafeteria, and we always had the opportunity to try an interesting snack. "*Two samosas for a couple of those chin chins?" "Ok deal! But next time I want to trade rotis!"* And when it was time to go home, our moms would be waiting outside in their bright and beautiful traditional clothing.

But quickly that changed. During kindergarten, my family moved to a small town in Pennsylvania. Now the only options for lunch were white or chocolate milk. Pizza or

chicken nuggets. Broccoli or carrots. When I brought my own lunch, everyone scrunched up their faces and covered their noses. *"Ew, what is THAT?"* So I learned to throw away my favorite kabob sandwiches. I left school hungry every day. I didn't want to eat their lunches, and they wouldn't let me eat mine.

I stopped asking my grandmother to put the braids in my hair when just a year earlier I cried if she made it any other way. I started getting angry with my mother when she tried to speak Urdu with me at the bus stop. I learned that my dad "spoke English funny", and that meant I had something to be embarrassed of.

But then we moved back to a city in Jersey, close to my aunts and uncles, back to a neighborhood that had plenty of others who looked like us, spoke like us, ate like, and now I wasn't THAT strange, once more. We moved a few more times in between, but always to places that were full of people of all different creeds and colors.

Then at the end of fifth grade my family moved from central Jersey to a small town in the heart of Southeast Missouri, smack dab in the middle of the Bible Belt. We were one of a dozen or so families who weren't white. We were one of five who were Muslim.

Being brown here meant being "weird," again. But this time, I had decided I wasn't going to be throwing away any lunches. I didn't care how many noses were offended. I had learned that my skin color wasn't going to rub off, and everything that came with it was here to stay too.

Yet, while I was still welcoming this newfound sense of self, another part of my being came under a form of constant scrutiny. That was something I was not yet prepared

for. My skin color and my culture had been one thing. But now my faith became another bullseye for others to smash, before faith was even a concept any of us could fully grasp.

***

Oh.

They were Muslim.

She didn't say anything else. I'm not sure she knew what else to say. Neither did I.

We stood there silently for a few minutes and then walked back into the classroom.

Now I paid attention to the bottom of the screen, the place where written news comes scrolling through: *Abdul. Ahmed. Aziz. Hamza. Hani. Fayez. Khalid. Saeed. Waleed. Ziad. Mohammed.*

Those were the types of names rolling across the screen. And I could pronounce them all.

These were common names in my household. They were common names in the communities I belonged to. They were the same names many of my family members shared.

Now I understood.

As I looked away from the screen I saw the looks on my classmates' faces. They had watched me get pulled out of class. They saw the news as they flashed the faces of the people who had crashed the towers. They saw the color of their skin. They heard their names, so far from anything that sounded like a Sam or an Ann. They read the rising death tolls.

Then they turned and looked at me.

They still do.

***

For Muslim Americans, experiences related to emotional/mental health are an intrinsic part of the lived experience of *being* Muslim in America. This chapter aims to highlight what it means to be a Muslim-American in today's time period. I utilize 9/11 as a normative history-graded experience, an experience correlated with historical time and experienced by the majority of a population during a given time, to set the cultural context of being a Muslim-American. History-graded normative events help describe how the majority of a set cohort of individuals experience an event in similar ways (Baltes, Reese, and Lipsitt 1980). I utilize 9/11 and the post-9/11 time period to make sense of my participants' experiences in the proposed historical context and I employ phenomenology to investigate when and how stigma plays a role in the ways which Muslim-Americans understand and define themselves.

Niyaz who had spoken at length about mental and emotional health, provided me with more context on how he had entered the mental health space. When I asked him what it was like being Muslim and living in Boston, he took me back to 2001 and described his own experiences on 9/11 and thereafter:

> *"I think I was around 13 or 14 when I started to not identify with Islam. Just the normal rebellious adolescent stuff. I was living in a very WASP-y town, not really a lot of diversity and I didn't fit in and felt ashamed for being different. Part of it was like I said, just dumb teenage stuff, but part of it was that I didn't identify with being Muslim at that time.*

But it was how others labeled me, the identity gets cast upon you, but I was a fringe kid. When 9/11 happened I was in high school and a kid called me a terrorist and I punched him in the face. We both got suspended."

This theme of being Muslim-American and the lasting impact of 9/11 came up in conversations with other participants, including my meeting with Mustafa, a half-Palestinian man in his early 20s. As we sat in the corner of a local kebob house, Mustafa's attempted to quietly smooth and tuck his curly brown hair behind his ear with one hand as he called the waiter with his other hand. Mustafa was a relatively quiet spirit and even in a busy kebab house, he brought with him an aura of calmness. As I asked him about his experiences in Boston, he briefly closed his dark green eyes, taking a minute to pause and reflect before speaking:

"Two events come to mind that have impacted being Muslim not just in Boston but likely in the United States.

The first is 9/11. I was in my junior year in high school at that time. But people knew me and my family and didn't think our family was suspicious. We didn't run into things like that. But after that is when I thrust into having a deeper look into my faith. I needed the wording to explain that Islam did not condone things like 9/11. To us (Muslims), if you kill an innocent person, it is as you've killed the entire humanity.
The second experience was the Boston Marathon bombing. Leading up to and finding out who did it and their backgrounds, that was tough. You pray, don't let them be Muslim. It's tough because then the world starts associating those terrible actions with a faith and a community.

I think our local Imams played a key role in helping to voice our(congregants) feelings and saying "Hey, this not what we as Muslims represent. We do not condone violence. We do not condone killing innocent people. We do not condone terrorism." I think it was around that time that Boston showed that as a

community, as an interfaith community we are very tight-knit. We received support from other Christian and Jewish congregations to say, "Hey we stand with you and we understand these two guys who had their own agenda." I think that was really important. In Boston they have be kind to thy Muslim neighbor signs posted in front of Churches, so it's just a different environment.

I know around the country it hasn't always been like that, there have been hate crimes against Muslims, but I haven't personally experienced it. I openly talk about Islam at work, my coworkers know I pray 5x a day and ask me about issues related to Palestine.
I have been really lucky, not everyone has had that same support."

While both Niyaz and Mustafa discuss their experiences with 9/11, they have largely different experiences. Niyaz discusses an "identity cast upon him" and Mustafa discusses it as a time when he was "thrust into having a deeper look at faith". While both men have vastly different interactions with their peers afterwards, both develop a more acute sense of their Muslim identity (voluntarily or not). The events of 9/11 resulted in these young adults becoming aware they exist not simply as Americans, but as Muslim-Americans and recognizing this distinction would impact the ways in which they would navigate and experience the world.

This distinct experience can be described as liminality, as 9/11 flipped the switch for these youth that created a "separation from a previous world" (Van Gennep 1960). 9/11 was as an event "outside of the peripheries of everyday life" that resultied in "newly achieved status" into a group (Turner 1974), in this case the group being Muslim-American. 9/11 functioned as a difficult but valid liminality where the children of Muslim immigrants recognize their identity, by interactions with others, as not as an American- but as a Muslim-American. For both Mustafa and Niyaz, post 9/11 brought

their identities as Muslim-Americans to the forefront and transformed how they viewed, or more accurately how others viewed, their place in the world.

With the idea of being placed into an identity group, like Muslim-American, I sought a framework to understand how identity groups, at-large, occupy space in a democratic society. Amy Gutmann's book *Identity in Democracy* (Gutmann 2004) points out that identities can be categorized by race, gender, sexuality, ethnicity, religion, disability, class, ideology, political party, national citizenship and many other types of social markers. Some argue that identity grouping constrains rather than liberates because it encourages stereotyping and denies individuals the freedom to be/ affiliate as they choose; and pits groups against other groups.

Others argue that identity groups "help individuals have a more secure sense of self and social belonging and propels disadvantaged groups to counteract inherited negative stereotypes, defend more positive self-images, and develop respect for members of their groups." In a democratic society, group identities are as abundant as they are controversial but Gutmann makes the argument that organizing ourselves on the basis of group identity is not a good or bad thing in itself, because long as individuals are free to associate, numerous identity groups will exist because "free people" mutually identify in a number of relevant ways, and a society that prevents this from happening, a society that prevents identity groups from forming is actually a tyranny. Gutmann states:

> "Once we recognize all these groups as identity groups, we are in a far better position to engage in nonpolemical analyses of the problems they raise and the contributions they make in a democracy. Here, in a nutshell, is the dilemma that identity groups present to democracy:

- Identity groups are not the ultimate source of value in any democracy committed to equal regard for individuals;
- Identity groups can both aid and impede equal regard for individuals, and democratic justice, more generally;
- Some identity groups promote negative stereotypes, incite injustice, and frustrate the pursuit of justice;
- Others help overcome negative stereotypes and combat injustice in contexts of civic inequality and unequal liberty and opportunity;
- Identity groups can also provide mutual support and express shared identities among individuals whose lives would be poorer without this mutual support and identification.

Why are identity groups not the ultimate source of democratic value?

> Equal regard for individuals—not identity groups—is fundamental to democratic justice. A just democracy treats individuals as civic equals and accords them equal freedom as persons.

People often join a group because they share an identity and therefore identify with the people represented by the group and want to support its cause. They usually don't join because they want some instrumental goods from the group that they could not otherwise obtain. Many members of organized identity groups could obtain the same instrumental goods even if they did not join the group. Why, then, do they join? The answer to this question should not come as a surprise (except to those who presume that all rational individuals act—and therefore join groups—out of self-interest). Shared identity is connected to identification with a group and, as a large body of psychological literature demonstrates, is independent of the pursuit of self-interest.

What distinguishes social markers of group identity is that they carry social expectations about how a person of the particular group is expected to think, act, and even appear. Social markers therefore contribute to the creation of collective identities of both individuals and groups. Collective identities can change over time, and they are also open to varying individual interpretations. Yet because these identities are collective, they may be very difficult for individuals who are so identified to change, even if they do not welcome the identification."

(Gutmann 2004, 7)

Niyaz provided further examples of how the transition into the post-9/11 period has impacted his own identification:

> *"Like I said I didn't identify with Islam from about the ages of 13 to 21 but others identified me with it. Now I wouldn't say that for me being Muslim is a religious identity but a I have accepted it as a cultural identity because at some point you become conscious of how the world labels you, who they think you are.*
>
> *You know that if you're a brown guy with any degree of facial hair and a weird sounding name you are going to get extra security checks. They aren't going to be asking you for your theological standpoints at TSA. That's why others like Sikhs are hurting along with us in era of anti-Muslim rhetoric."*

For others like my participant Maria, she pushed the anti-Muslim rhetoric with perhaps a "pro-Muslim narrative". Maria had a very energetic and, at times, exhausting personality. She worked in media, spoke a million miles a minute, and honestly reminded me of a bouncy ball. When we met for the purpose of the study, she rushed in thirty minutes late in a bright orange blazer and plopped down on the seat across from me.

At the ten-minute mark I had thought perhaps she wasn't coming and had decided to sprawl my papers all over the table. Now as she sat down, she grabbed one of my papers and said *"I'm so sorry….oh what is this sweetie?"* having picked up one of my papers. And before I could reply she jumped into a story about a news piece she had been covering.

> *" So after my friend got accused of using a pressure cooker to develop a bomb, except he was actually working on testing water pressure for developing countries, I started thinking about what he is contributing immensely to society and the story could have been about what he was creating but instead they just reported on how he had been discriminated against.*

And then when people read these stories, if you read the comments people are like "Blah, Blah, Muslims complaining again about being discriminated against but who cares because they are terrorists."

Since 9/11 there's only two types of stories told about us and both types are negative.
*We are always portrayed as either the terrorist or as the victims. We are never going to break past the clusterfu*k of stigma surrounding being Muslim in this day and age if those are the only two types of stories we tell. Like okay yea, good to get our voice out and express how we are treated differently or marginalized but if we only get ONE chance to speak in the media we want the best story told, and that's not the very best story. Its not the most accurate story. Its only a fraction of the whole picture but the media seems adamant about only telling those stories.*

Muslims don't want those to be the only types of stories that are told, they want positive stories to be told. I think other people too (non-muslims) would be surprised and refreshed to see those stories that's like "Oh hey wow Muslims are incredibly smart and dedicated and doing fantastic things for all of society."

We are craving to tell the positive stories. From our fields to our careers, we want to showcase our stories to show we are making an impact, we are doing good work, we are leaving a cultural footprint as Muslim-Americans. These are the types of stories that need to be told, these are the types of stories that most Americans, or actually most people around the world don't know about us. I want there to be human faces, pictures, to showcase the positive side of Muslim-Americans.

I am conscious of how the media can shape a narrative, how it can downplay a narrative or actually incite hate, but it can also help unite. And that's what we need right now.

As I listed to Maria speak, I realized that while I never actually asked my actual question about what is was like being a Muslim-American in Boston, I still received a response. Maria's commentary on how the Muslim-American community has been

portrayed as either a "terrorist" or "victim" since 9/11 and how it should be portrayed in a positive light as a strategy to help change the narrative is pushed back upon by others.

Niyaz states:

> *If you don't have to think about that, if you don't have to think about politics right now – then that's a privilege. Because people who look like us, they don't have a choice. I do work to put my true self out there through art but that's not the first thing people are ever going to see. And you have to understand some people might never see you for who you are because they simply don't want to.*
>
> *I had this roommate back in the day, he had spent so many nights at my parents' house with me, he had spent Thanksgivings with us, and when I found out he is a Trump supporter- that changed things. When I tried to talk to him about it what he really thought came out, and it hurt. This was someone I had trusted and thought he understood us, but I was wrong. We don't talk anymore.*
>
> *This Trump era political rhetoric, it takes a toll on you, on your life, on your mental wellbeing. It's complicated and it can't be changed just by inviting people over for thanksgiving. It has been acceptable to treat Muslims less than human and that is what has to be changed.*

In Niyaz's discussion of the post 9/11 to the current "Trump era" he details the transition of having embraced Muslim-American as a cultural identity, because he is not afforded the choice not to, "if you don't have to think about politics- that is a privilege". Niyaz points to examples where politics have begun to play a role, like airport security and friendships, due to a political transition of identifying Muslims in the current time period. This political transition is reminiscent of Samuel Huntington's 1996 *The Clash of Civilizations and the Remaking of World Order* and 2004 *Who are We? The Challenges to America's National Identity*, the latter which aims to divide America into two cultures and the former which aims to divide the world into two- saying that future wars will not

be fought between countries but between cultures and he then pits Islam as an "other" stating that "Islamic extremism is the biggest threat to world peace". Huntington's divisive views seem to have an unfortunately helped shape America's current political and cultural developments. One participant details how this has played a role in her daily lived experiences.

Yasmin was one of the women I had met with during my time at the Blue Mosque. At 5 foot 9 inches and always dressed in flowy, light colored abayas with arms outstretched to warmly welcome those who walked through the mosque doors, Yasmin was nothing short of a real-life angel. During my time at the Blue Mosque she had been instrumental in helping me get set up and letting others know of the work I was doing. Because she had been my biggest supporter, others had followed suit. So now as I listened to her recount experiences where people who knew nothing of her true faith, told her what it meant:

> "*In Somali households the hijab is something all women wear when they are of age. I started wearing it right before 9/11. The day you start wearing it everyone knows you are Muslim. It's a symbol of your faith that everyone can see and there are those people who do not know anything about you, but they know you are Muslim because of your hijab.*
>
> *There have been a few times where men have told me to go back to my country, or told me they wanted to rip it off, and once a man spit at me on the train. Why they feel the need to do this? It is because of fear that has been spread through the media.*
>
> *I have been hearing the fearmongering for years since 9/11 and I know it is simply not a true depiction because I live as a Muslim, I work with Muslims. But if you don't know a Muslim, it's not an excuse to show hatred, but I can understand the fear, and people have learned to be fearful because of the media. It's not fair and it wears us down, but at least knowing why something is happening can help ease the pain.*

For example, sorry I am going to use an example from my own research, but the HIV/AIDs epidemic people were so scared of how it spread before that they kicked people out of communities, burned their furniture, and wouldn't touch them. Princess Diana helped show that wasn't true by shaking an affected man's hand without gloves on TV.

I don't mean to compare Muslims to the HIV/AIDs epidemic but sadly it also isn't that from the truth as to how we are portrayed in the media, like when they say sharia law is infecting the United States.

While Yasmin details her own lived experiences of being Muslim in America she also points to what is spreading the fearmongering, the media. In the 1980s the term 'Islamophobia', which was introduced (Conway 1997), and it is increasingly used to describe this fear of Islam and of Muslims as a social group. There is a continuing rise of Islamophobia in not only the United States but many Western majority populations, perpetuated by Western media (e.g., Poynting and Mason 2006; Saeed 2007)

In a society where cultural diversity is not celebrated, immigrants cultural identity is subjected to discrimination, stereotypes and prejudice. Individuals' self-concepts are largely based upon their social identities derived from various group memberships (Hogg and Terry 2000), so individuals who perceive that they lack the resources to deal with being a target of stigma may experience additional trauma (Major, Quinton, and McCoy 2002). Being Muslim brings with it certain stigmas as Poynting and Mason (2007) point out, there has been a shift "from anti-Asian and anti-Arab racism to anti-Muslim racism" (p. 61) and this has been heightened following the terror attacks of 9/11. Now political debates focus on questions regarding Muslim immigrants, who are often seen as "difficult to integrate" (Field 2007), and many right-wing individuals and political parties promote

the idea of "insurmountable cultural differences", creating an atmosphere of "othering" and hostility (Betz and Meret 2009).

Hamid Dabashi's 2001 *For the Last Time: Civilizations* critiques the works of Samuel Huntington and others like Francis Fukuyama and Alan Bloom, academics from "elite" institutions who have helped propagate the anti-Muslim rhetoric into mainstream American discourse. Dabashi argues that the likes of the aforementioned helped create a strategy for raising "a fictive Centre for European modernity and lowering the rest of the world as peripheral to that Centre" and that strategy has been the creation of the binary opposition between Islam vs. The West, which has turned into "Muslims completely (but not entirely) replacing Jews as the civilizational *other* of the thing that calls itself `the West`" (Dabashi 2001). This is constantly narrated in mainstream discourse with statements like those of the President of America stating "I think Islam hates us. There's something there. There's a tremendous hatred there. We have to get to the bottom of it. There's an unbelievable hatred of *us.* "

Kleinman and Farmer have explored the ways in which structural violence and social suffering impact daily life. The "othering" of Muslims, as Dabashi describes, can be understood through social suffering which results from "what political, economic, and institutional power does to people and, reciprocally, from how these forms of power themselves influence responses to social problems" (Kleinman 1997, ix). This approach helps to highlight the political and social origins impacting suffering that is derived from exclusion and discrimination which is transformed into emotional distress, as Maria, Niyaz, and Yasmin all allude towards. Maria discusses a "craving to discuss positive

stories" while Niyaz states the "political rhetoric, it takes a toll on you, on your life, on your mental wellbeing" and Yasmin echoes those sentiments stating, "It's not fair and it wears us down" – all giving way to understanding the social suffering experienced by Muslim Americans.

Suffering is collectively rooted "the often close linkage of personal problems with societal problems. It reveals too, the interpersonal grounds of suffering: in other words, suffering is a social experience" and "we put in that category of social suffering every different kind of human problem that creates pain, distress, and other trials for people to undergo or endure. We do not, for example, separate illness from political violence or from other forms of misery" (Kleinman, Das, and Lock 1997, 15), which helps put into context how the "othering" of Muslim Americans is shaping their responses.

As showcased by the conversations above- identity of *being* Muslim in America is a stigmatized identity. Muslim-Americans interstitial identity is compounded by socio-political frameworks impacting mainstream American narrative. Utilizing this framework allows us to gain a better understanding of Muslim Americans mental health, allowing us to incorporate the macro societal processes which contributed to the social suffering of Muslim-Americans.

CHAPTER 6:

"THAT'S WHITE PEOPLE PROBLEMS"

Empire (Daniels and Strong 2015)

1998...

I stood behind the hallway door, as still and silently as I could. I was supposed to be asleep in the other room, but here I stood, quietly listening. Occasionally peeking past the big brown door, trying to catch a glimpse of the scene. And there were the adults, huddled together at the table. With their heads resting on their hands, and listening to each other, without saying a word at all.

Something had happened. Something bad. But no one was saying it out loud. And somehow I knew why, I knew it was something I was never to ask about, never to bring up. Never to admit I heard what was not said.

That night I snuck back into the living room, to my usual bed, the decades old green and yellow flowered couch. It was ugly but it was soft, and it was home. As I lay back down, the couch sucked me right in, back to my normal spot. I glanced over to the floor. There lay my grandfather with my baby sister and brother who had clambered on top of him, along with a stuffed animal or two, dozing off without a worry in the world. But my grandfather, his eyes were open, and they were filled with tears. I quickly closed my eyes and rolled back over.

I knew why he was crying. I wanted to reach out and give him a hug, but that would mean revealing what I knew. And right now was not the time.

***

Building upon the Chapter 4 "Completely Mental" discussion of the limitations of biomedical terminologies in addressing the emotional/mental health of Muslim Americans and the Chapter 5 "I think Islam hates Us" discussion on how Muslim Americans face additional challenges due to perceived "dangerous religious identity" and "othering- this chapter expands upon that argument; the mainstream American narratives of mental health care and support do not adequately reflect nor accommodate varying approaches to personhood and well-being relevant and necessary for Muslim-Americans.

I now revisited the literature of mental health in anthropology with a keen awareness of social suffering with an aim to further explore the political economy of

health. I relied on the "macro-analytic, critical, and historical perspectives for analyzing disease distribution and health services under a variety of economic systems, with particular emphasis on the effects of stratified social, political, and economic relations within the world economic system" (Morgan 1987). What I landed upon was how non-normative experiences by Muslim-Americans, created social exclusions not only from other identity groups but also within their own identity group of Muslim-American.

The impact of the first two types of experiences: age-graded and history-graded are more easily defined influences, but this third type of influence(s)- a catch-all-term to encompass and account for all other types of periphery experiences can be difficult to categorize. Muslim Americans as a collective are difficult to lump into one category. Similar to the woven cultural fabric of America at large, Muslim Americans hold a spectrum of various beliefs, behaviors, ethnicities, societal expectations, preferences, and socioeconomic classes, making them amongst the most diverse minority groups in America today. Thus, instead of forcing heterogeneity to conduct an analysis, I instead narrate the impact of these non-normative influences as voiced by my participants. The non-normative life events provide a key look into individual differences and are necessary in understanding the vast range of beliefs and experiences when studying a group as diverse as the Muslim-American community.

As discussed in previous chapters, discussing actual experiences related to mental health was the most challenging part of the study. While the National Institute of Mental Health data (November 2017) shows that nearly one in five adults in the United States (44,700,000 individuals) live with a mental illness, only about half ever seek any type of

treatment. With concerns about stigma and discrimination, I sought to explore how Muslim-Americans utilized resources and services related to emotional/metal health. I spoke with my participants to learn more about this phenomenon and to learn if perhaps the the anti-Muslim narrative in some ways made it easier to discuss emotional distress within the Muslim-American community.

As Yasmin and I continued our discussion, I could not help but admire her strength. When she had previously spoken about the man who had spit on her, I knew that she had been hurt by the way her eyes looked down and her voice dipped low, but she did not let such experiences keep her down, within a few moments her voice returned to its normal tone and I decided to inquire about what helped her recover from traumatic experiences:

> "*I've learned to not let it bother me so much, my faith in God and the Boston community that helps me keep going.*
>
> *I am blessed that I get to come here (Blue Mosque) every day and I get to make a difference. Through the mosque we have helped people find their footing, whether it is getting a job to pay the bills or finding them an attorney to help them with their immigration or being there for each other in the times of need, Alhamdulillah..*
>
> *It is my connection with others and the support we provide each other that helps me keep going. I think that is what faith does, no matter which faith tradition you belong to, it is trusting in God that things will get better, Inshallah, and as believer working towards continuing to do good."*

Yasmin's use of "Alhamdulillah" and "Inshallah" was an important part of her vernacular which was tied to her beliefs of remembrance and appreciation of God. She was conscious and cognizant of her every day actions and of how her careers was dedicated towards building a better humanity, something that was inspired by her faith.

As I listened to Yasmin I reflected upon my own experiences that had led me to conduct this research. The story noted in the beginning of the chapter, of when I lost a relative to suicide, and my own journey to ensure that this would not be a continued trend. For me healing also came in a God-centric form of healing, through the three-tiered levels of my faith:

- Islam- the first level- *accepting* that there is no other God but God and that Muhammad is His Messenger, and worshipping through physical actions/rituals. (Is a Muslim)
- Iman- the second level- *believing* and submitting to God by working towards acquiring a deeper level of knowledge, embracing the metaphysical aspects of Islam. (Is a Mumin)
- Ihsan- the third level- derived from the Arabic verb "ahsana," which means doing things better, the literal linguistic meaning of Ihsan is doing and giving one's best, excellence. (Is a Muhsin)

As Yasmin references faith as a tradition that teaches us to be *Muhsins*, or doers of good. Ihsan requires a sense of social responsibility, sincerity, and gratefulness- constituting the highest form of worship through excellence in work and in social interactions and she states this is what she is working towards by working at the Blue Mosque. Similarly, Ihsan has always been a major determinant in my life choices. [10] Emphasized in my household, from an early age, to learn how to make choices that benefit the collective. This same belief has led into my work on Muslim Americans, The

[10] Well both the concept of Ihsan, and also my dad whose name is Ihsan.

importance of this is cited by other studies like Padela et al. where "Participants shared a God-centric view of healing. Healing accessed through direct means such as supplication and recitation of the Qur'an, and indirect means: human agents including imams, health care practitioners, family, friends, and community. Human agents served integral roles, influencing spiritual, psychological, and physical health. Additional research into how religiosity, health care systems, and community factors influence health-care-seeking behaviors is needed" (Padela et al. 2012)

Yasmin's preference for receiving support comes from a connection with God and with her community which is similar to Bagasra's (2011) work that Muslim-Americans tend are more likely to seek help from family and friends than to seek help from mental health professionals" (Bagasra 2011). I found community support to be a polarizing issue. In some situations, those related to feeling "othered" or ostracized by political rhetoric- emotional distress related to those issues could be discussed in a community setting without the fear of judgment of "outsiders".

Yet, for other issues, those which would likely be considered taboo by other Muslims, seeking community support was not an option- now there was a fear of judgment within the community. For non-normative experiences I will focus on two participants, Bisma and Laiq, whose stories we have not heard yet. For all other participants you have already heard from, I will give provide their examples of non-normative experiences with short snippets below but refrain from going into too lengthy of a conversation. By no means is this a method of erasing or minimizing the other eight participants lived experiences but Bisma and Laiq presented two very unique stories that

tie together many of the themes that other participants had also mentioned and experienced.

- Laila:
    - Anxiety and Anorexia

      "So I suffer from anxiety disorder like generalized anxiety. I first started feeling this, well I guess it's been in my life for a while. But I didn't really know what it was. When I was younger, and I would always feel anxious like whenever my mom was getting mad or like I'd be scared of getting caught and then I would let that just roam in my head and over analyze it and just be like Oh my God. My God. Oh my God.

      And I remember this being something I'd do when I was five or six. So it's kind of just always been in me and I think it really got bad in college when I just felt really overwhelmed with school and I found myself not able to make decisions and I would start panicking and I started having panic attacks in college and that's when it just got bad.

      Then there was a point in college I wasn't depressed, but I was just numb. I didn't really feel anything, and it was a scary time because I didn't know what that feeling was and now I still am dealing with my anxieties.

      And oh yea, I also have anorexia. I think for me with anorexia wasn't just about control, l I think it also at some point became I never felt pretty enough. I like the way my face looks when I'm really skinny, I know that's bad to say. But I feel like when I gain weight in my face, it's not a beauty thing about pleasing others but a personal issue for myself. Because it doesn't fit what other people say or think. Like those of us who are not white are apparently supposed to "become white". Like we should have fair skin and what not, I don't (have fair skin) and that never affected me. American culture it's all about being skinny but other immigrant it's about being healthy. So they like people that are not fat but with fuller figures, curvy. Basically we are meant to have big hips and big boobs, everything. I don't have any of those ASSets (laughs)"

- Noora & Ibrahim:

- Dealing with family members who were mentally ill

- Raheem:

  - Dealing with Domestic Abuse

    "Things were not always great, or even good, in our home. There was domestic abuse for years and years. But no one knew, outside our house no one knew. It is just not something we talk about. Its something I still don't want to talk about. I'm just telling you because people need to know it exists.

    Islam helped me get through it. Nowhere in Islam is it okay to abuse another human being, in any damn capacity. The way many, especially our parents the way these people interpret Islam is so rigid, so dogmatic, but even with these narrow interpretations, they still can't justify that behavior. Our cultures are more problematic than our religion. We don't even know the differences."

- Mustafa & Niyaz:

  - Depression

    Mustafa: "When I was in middle school I had a lot of trouble with loneliness. I had a couple people who gave me ideas on how to better myself. I learned things from sports and then just from having faith in God.(Discussion about remembering God in vernacular)

- Yasmin:

  - Dealing with Divorce

    I got divorced after just two years of marriage. It caused a drift with my parents too. But I had to do what was right for me. Islam doesn't say anywhere that divorce is not allowed. It is allowed. It's okay if things do not work out. Working at the Mosque, I can help others understand these issues now.

- Maria:

  - Bipolar Disorder

****

Bisma and I met at her home. As I stepped inside her home, I removed my shoes in the entryway and she then led me towards the living room. She had tea and biscuits ready to go. As I got comfortable on couch and pulled out my laptop Bisma pulled her long brown hair into a bun and sat in a chair across the table, squirming. I asked her if she was alright and she gave me a nod.

She had heard of my study through a friend and wanted to share her experiences so that maybe one day they would help someone else, but she was also terrified to reveal what she had to say. Having been brought up in an Afghan household in the South, Bisma embodied strict Southern values that aligned quite well with her household's strict Muslim values. Bisma was now an immigration attorney who helped families like her own, who had come to America seeking a better life.

Patiently, I waited to get the interview started. We went over the IRB, the demographics form, and eased in with the "emotional health" questions, eventually Bisma said, "I have something to tell you" And so we started:

> *"When I graduated from law school, I was having a really tough time. My family wanted me to get married. I had been seeing someone all throughout law school. He was Muslim too. Also Afghan. A doctor. Everything my parents would have wanted. And I thought things were going to work, I thought I could make it work, that at some point he would start treating me right. But that never happened.*
>
> *It was my first real relationship, so I didn't really know what to expect but looking back it was so, so toxic. I think all of that clicked after I got pregnant.*
>
> *When I told him, he screamed at me and told me he would never marry a whore. I had lost my virginity to him, and he was the one who constantly cheated on me. The abortion was my only option. But I miscarried because of stress before I even got the abortion.*

I had no one to talk to about it. I couldn't let anyone know that I had had sex, worse that I had gotten pregnant, and the worst that I was having an abortion.

That was a really, really rough time for me. I didn't even know where to start for help. I was depressed for a very long time. I felt like a terrible person. It confirmed that I was a terrible Muslim. Who would help me? It took me a really long time to get healthy.

I asked Bisma, "How did you finally start to get better? How did you get to where you are today?" She replied:

"I had no other option. Either I was going to get help, or I was going to kill myself.

When I had gone to the gynecologist after the miscarriage, she had recommended that I go to therapy. After a few months of not getting out of bed I had a friend who told me that whatever was going on with me was not healthy and that I had to go to therapy. I never told her what caused me to be so depressed but her talking to me about her own vulnerabilities made me find the strength to finally go to the woman the OBGYN recommended. There was nothing more I could lose. That therapist had worked with lots of other young women. She told me that I wasn't alone and that I wasn't the only person this happened to. She saw me twice a week, she let me pay on a sliding scale, and I don't know when it happened but after a year I finally felt like I could have my life back.

That's why I'm talking to you about this today. If I had known this had happened to another Muslim girl, that I wasn't the only one, then maybe I wouldn't have blamed myself for everything. We make mistakes in life, but as young women we are prone to perfectionist tendencies, and when something bad happens we put all the blame on ourselves. That isn't healthy.

And the man who had gotten me pregnant, he didn't struggle. He wasn't in bed for months, he wasn't out of a job for two years. He just kept on destroying other girls lives.
I was the one who had internalized everything. I was the one who wore the weight of the stigma. I was the one with the scarlet letter."

Bisma's story highlights the intensity and depth to which the stigma of her experiences had impacted her life. Since Erving Goffman's initial definition of stigma in the 1960s- the concept of stigma has undergone significant modifications. Goffman

originally described stigma as a process based on the social construction of identity, including both psychological and social elements, to illustrate how those with a stigmatized condition went from “normal” to a “discreditable” social status. Kleinman and Hall-Clifford challenge the study of stigma 1) leaning too heavily on psychological approaches, 2) insufficiently incorporating “understandings of stigma and stigmatized individuals as embedded in local moral contexts” (Kleinman and Hall-Clifford 2009).

Kleinman and Hall-Clifford argue that the limited study of stigma has failed to include how social life and relationships are changed by stigma. They point out that sociologists Link and Phelan (Phelan, Link, and Tehranifar 2010) have provided a model of stigma that includes a component of “structural discrimination, or the institutionalized disadvantages placed on stigmatized groups” that can help us begin to explain the ways that political, economic, and social power can shape the distribution of stigma within a social environment.

Additionally, Yang & Kleinman’s recent anthropological studies on stigma have focus on “stigma as embedded in moral experience” and on “the stigmatized as a person with a moral status”. They discuss how the moral standing of an individual or group is determined by their “local social world and maintaining moral status is dependent on meeting social obligations and norms. Individuals with (or associated with) stigmatized conditions are de facto unable to meet these requirements” (Yang and Kleinman 2008; Yang et al. 2007). This brings to light the fear Bisma has of being “a terrible Muslim” and not having a place to turn for help due to the moral stigmas attached to pre-marital

sex and also the implicated in stigma in going to therapy, as she went only when "she had nothing else to lose."

Furthermore, as she points to signs of emotional abuse, Muslim-American women's experiences of abuse remain largely unstudied, but one study that comes to mind is Hassouneh-Phillips' (2001) narrative study that illustrates the process of leaving an abusive relationship from a very traditional sense. It highlights four stages, with the first of reaching the point of saturation, the second of getting khula (an Islamic divorce initiated by wives), the third facing family and/or community disapproval, and the fourth "reclaiming the self." This study in and of itself highlights some of the moral stigmas as to why Bisma, an unmarried woman, who had experienced a toxic relationship, would not be willing to discuss it because even in research the studies focus on women who were married.

Kleinman & Hall-Clifford note, "stigma decays the ability to hold on to what matters most to ordinary people in a local world, such as wealth, relationships, and life chances…..although stigma may share features across contexts, it uniquely affects lives in local contexts" (Kleinman and Hall-Clifford 2009). My next participant's story demonstrates how stigma decays relationships.

Laiq's story is also one that does not easily come up in Muslim circles. Laiq, a young half Pakistani, half-Egyptian man in his early 30s told his story of achieving and then destroying "his dream". With an unkempt beard, and ruffled hair, Laiq forced a smile at me as he walked towards the back of the cafe. Tall and lanky, he struggled not to knock over coffee cups while making his way through the labyrinth of tables. He sat

down with a plop and after a few minutes composed himself to tell his story with a lens that was somewhat removed from himself:

> *"Well at first I was every Muslim parent's dream. I worked really hard in college, but I partied even harder. They didn't know. No one did. I was struggling with this emptiness inside and thought that the heavy alcohol and drugs would get rid of the feeling.*
>
> *It didn't make a lot of sense to me. I came from a good home. My parents had worked really hard to give me a life that was a thousand times better than what they had. But something inside of me was dead. I felt like one of those spoiled rich kids who just needs something to fuck up. I had been given everything and there I was struggling with (puts fingers in quotes) feeling empty. Nah, that shit is for white people. Immigrants and their kids don't have time for that. My dad had literally hustled from the streets of Egypt to get to where he is.*
>
> *But that feeling wouldn't go away and so I kept drinking. Fast forward a few years and I got in to med school, and then I got kicked out. I don't really remember what it was like when my parents found out, I was in a drunken haze for most of those years. In and out of hospitals. I tried to kill myself three times. You think you'd be better off dead than living in this world with the reputation you've earned yourself.*
>
> *It finally changed when one night I had gotten so drunk one night and passed out on a bench about a mile from my parent's house. The cops picked me up and asked me why I hadn't just gone home. I felt so ashamed with them driving me home the morning of my parent's wedding anniversary. That's when I decided I was going to quit.*
>
> *I struggled with medication on and off. What helped me most was a friend who would drive me to AA meetings almost every day for six months. That community support is what saved my life. But it does get weird sometimes being a Muslim at AA meetings because its so Christian heavy. For me spirituality is more present so for the most part I just looked at it as "We're all fucked up here and trying to get better"*
>
> *The Muslim community wanted nothing to do with me during that time. Everyone just thought if their kids hung around me they'd end up like me too. It took a lot of*

hard work on my part and my parents. I feel really bad for what they had to go through because of me. I know they blamed themselves and I know that the community blamed them too which didn't help. It took us time to realize you can't blame yourself for a disease. You don't get sick because you did something wrong.

Now we talk to others about it. If someone's kid is struggling, they ask me for help. I think if there's one thing that I can say- you can't get better until you are willing to put in the work to get there. It takes a ton of discipline to manage any disease.

I talk to Muslim kids about the signs of serious mental illness, I talk to them about that sometimes you have to get past halal and haram because that can be limiting. People aren't haram(taboo), you aren't haram, you're a human being.
Our community needs better ways to talk about what's wrong and right, you can't make people feel like they are immoral for having a disease. That's never going to help anyone get better.

I think other people can skew judgment too because they can start putting blame on you for certain things you think. I think my issue with that is sometimes the Muslim community is they will blame you in some way for having mental issues. Like they will be it is because you're not praying or you're not praying the right way. See you're not praying. So then you pray more but I think there are some things that like can't be fixed by praying.

So I talk to kids about and triggers and toxic environments, and not everyone has to go to med school. That shit is toxic for real. There are plenty of ways in which we can help make the world better. I still became a "doctor", I got my PsyD, and I struggled like hell but now I can help people, so they can talk about it, and start the process of getting better.

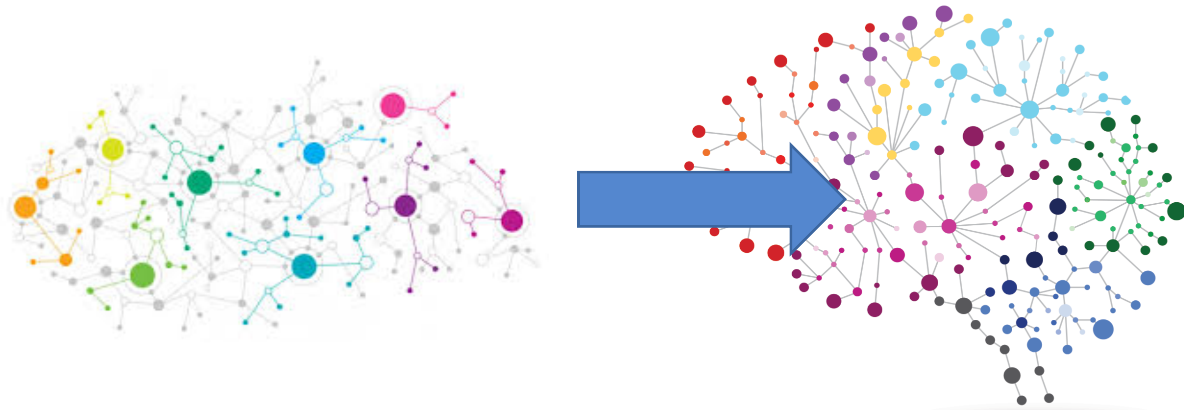
Ethnographic methods, like Laiq's story, help measure cultural value systems enacted in people's lived worlds and facilitate understanding of stigma and its outcomes. Laiq's journey with depression and alcoholism evolves from feeling ashamed and helpless to feeling like he can make an impact because of his experiences. His story contributes to

the discussion of the altering his inner moral worlds which leads to change not only for himself but also his family and community as he uses his experiences to highlight certain points to others in similar positions. We only have to look to the examples of depression and smoking in the U.S. context to see that the relative stigma of specific conditions and actions can and does change across time.

Laiq's experiences show a significant trend toward his own internal destigmatization by gaining an understanding of the shifts in norms and moral processes that undergird stigma. Laiq's story, like the story of my other participants' points to how the moral standing of individuals in their local context, in this case as part of the larger Muslim-American community, affects the transmission and outcome of stigma.

CHAPTER 7:

FROM FRAGMENTAL TO FUNDAMENTAL



Chapters 4, 5, and 6 utilized Baltes, Reese, and Lipsitt's (1980) life-span development processes to categorize and discuss the different types of stigmas that Muslim-Americans experience with regards to mental illness.

Chapter 4 "Completely Mental" focused on the first category of age-graded experiences and found that participants held internal stigmatizing beliefs related to the language of mental health. The social stigma of mental health which penetrates one's thinking at an early age leads to individuals own internalizing stigma about mental health. One participant recalled having a break down in grade school, from other children calling him terrorist and sandn****r after 9/11, having to go to a psychiatric ward and then coming back to school only to have the other children now call him "psycho" in addition.

When individuals have grown up experiencing these types of events or seeing someone else experience this type of event, mental health become a topic of shame and embarrassment that one learns to stay far away from. Participants mentioned how these types of experiences taught them to become reluctant from acknowledging a mental

illness or seeking treatment because there is imminent risk of facing severe social discrimination and isolation. Individuals mentioned strong feelings of discomfort and feared that disclosing any type of impact from or with mental illness would cause their peers, friends, and even family to treat them negatively, or avoid them altogether. Mental health was certainly not a label my participants wanted to be associated with, and multiple times throughout the interview process many participants asked me to confirm that their story would be anonymous.

My findings suggested that emotional wellbeing was a more accessible term to discuss mental health- I believe we can work to build even better language around what are specifically signs of mental distress, signs that tend to be labeled and dismissed as phrases such as: “worrying too much”, “laziness”, “personality” or “attitude” issues.

One of the most important things we can do in regard to de-stigmatizing the language around mental health with regards to age-graded experiences is to increase education and improve public awareness around mental health, starting at a young age. If we don’t recognize that something is wrong within ourselves, or with our children, it’s unlikely that solutions will be sought. Educators and staff within institutions and organizations ranging from early childhood to graduate level studies can be trained to recognize the signs of mental distress and have some type of consistent dialogue built into their curricula which engages pupils to discuss and learn about mental health through a positive framework.

Additionally, these organizations can engage parents through community workshops and train them on how to have conversations with their children regarding

mental health. Such workshops could work to educate parents not just about their children's' mental health needs, but simultaneously their own since they likely did not grow up with similar resources during their own childhood. As noted in both Chapters 4 and 5, cultural perspectives can pose as barriers when working to eliminate stigma so specialized trainings that understand and can address cultural concerns will need to be utilized in such trainings.

Chapter 5 "I Think Islam Hates Us" touches upon how cultural perspectives can shape additional stigmatizing approaches. With an emphasis on history-graded experiences, pre and post 9/11 became normative history-graded experiences for all Americans but for Muslim-Americans, being Muslim now became a stigmatized identity and Muslim-Americans became "othered" from the Americans at-large, at times having to "come out as Muslim".

Participants discussed experiences of discrimination solely for being Muslim. Many spoke of the distress it caused them to be Muslim-American in this day and age but voiced concerns about seeking mental health care from professionals who might not be able to or empathize with their experiences. Some participants who self-disclosed long battles with emotional or mental health difficulty, reported that they did not seek help specifically for this reason. They believed that talking about their emotions and thoughts in regard to be Muslim-American would do more harm than good; and they reasoned that "we are not the only group this has happened to", that other groups have been used as scapegoats or persecuted in the past- and this stigma alone wasn't enough for them to seek out mental health. Some of the participants that did seek out therapists ended up

receiving very irrelevant advice. One woman who had sought help related to work-induced stress was instead if she was allowed to work outside the home to begin with since she was Muslim.

Other participants spoke about how mental health providers were unable to understand or distinguish their religious/spiritual beliefs from their cultural beliefs and/or behaviors. They discussed how some providers assumed everyone of similar background thought and acted in a specific way- lumping them in one category and failing to see them as the sum of who they were. One participant discussed how she had gone to see a physician about feeling very down and instead her physician asked about her diet and weight and lectured her about the risk she held for diabetes as a South Asian woman.

The types of experiences mentioned above make it particularly difficult for Muslim-Americans to access help and instead leave them feeling that mental health care is ineffective. Discussions led to how the general public at-large views Muslims in a very homogeneous manner. Individuals discussed “what a Muslim looks like” in media (long beards and headscarves) versus what many Muslims look like in reality. And the reality is that Muslim-Americans are as broad in their backgrounds, beliefs, and behaviors as all other Americans. While this diversity across the group makes it increasingly difficult for some Muslim-Americans to seek care outside their community, it also makes it incredible difficult for some Muslim-Americans to seek care within their communities.

Chapter 6 “White People Problems,” built upon “I think Islam Hates Us” and focused on non-normative experiences that participants had undergone which could be deemed taboo within the Muslim community. They discuss being fearful of negative

outcomes in sharing their experiences with anyone, especially other Muslim-Americans, and this creates additional internal stigmatizing and a fear of social exclusion from their own community. Individuals discuss privacy concerns that information could be leaked by telling anyone, even a health provider, and this could create additional burdens for the individual and his/her families. Participants seem to take a cultural relativism approach where they judge themselves quite harshly against various Islamic principles they seem to be utilizing as a guide to distinguish between right and wrong.

However, I would like to challenge this view by stating that fundamental principle of Islamic morality is love: love for God and love for God's creatures. The purpose of this principle is for humans to treat each other with love and kindness to please God (IslamReligion.com 2009):

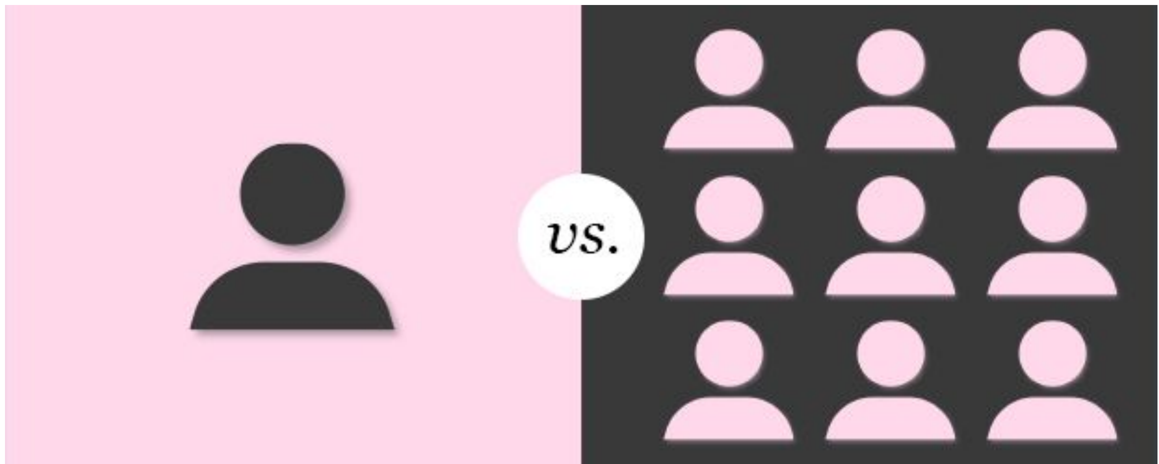
> *"It is not righteousness that you turn your faces towards the East or West; but it is righteousness to believe in God and the Last Day and the Angels, and the Book, and the Messengers; to spend of your substance, out of love for Him, for your kin, for orphans, for the needy, for the wayfarer, for those who ask, and for the freeing of captives; to be steadfast in prayers, and practice regular charity; to fulfill the contracts which you made; and to be firm and patient in pain and adversity and throughout all periods of panic. Such are the people of truth, the God-conscious." (Quran 2:177)*

Others discussed how they felt guilty about their experiences with mental illness. Participants mentioned how their parents told stories of how they walked many miles to school by foot and how they came to America with only $20 in their pocket. As one participant described "the immigrant hustle" is focused on making sure you had a roof over your head and food on the table. Utilizing Maslow's hierarchy of needs, that meant the immigrant hustle focused mostly on physiological needs.

Figure: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4130906/ (Henwood et al. 2015)

https://www.simplypsychology.org/maslow.html

Yet, many of the immigrant backgrounds my participants belonged to ascribed to collectivist cultures where love and belonging are very important themes. The duality of being from a household that ascribes to a collectivist culture and being an American that prescribes to an individualistic culture alluded to tension in my participant's voices. The conflict didn't allow one the ability to evaluate their own suffering because one must understand his/her suffering with relation to other's suffering. Figure



Individualist* (typically reflect western ideals)	Collectivist† (typically reflect eastern ideals)
Independent	Socially interdependent
Self-reliant	Connected
Achievement orientated	Moderate/traditional
Competitive	Cooperative
Assertive	Obedient
Pleasure seeking	Self-sacrificing
Self-assured	Sensitive
Direct	Self-controlled
Self-interest	Equalitarian

(Vinall, Pillai Riddell, and Greenberg 2011)

Thus, one's own problems didn't feel as serious, so individuals learned to remain quiet and over time it became difficult for them to express or communicate their feelings. However, one point of interest was the individualistic trait of self-reliance served as the collectivist trait of self-sacrificing by choosing not to seek help. Yet, I would argue whether someone belongs to an individualistic culture or a collectivist one, or a combination of both- humans require the same type of needs. Returning to Maslow's

hierarchy of needs, safety and health is a fundamental need and this included mental health. While I do believe that Maslow's hierarchy of needs perhaps categorizes human needs in too simplistic of a manner, beginning with a model that considers person-centered mental health is a step in the right direction. Participants discussed how they only sought mental health when they had "nothing else to lose", and no one should have to wait until that point before they can even think about accessing help.

* * *

For Muslim-Americans the age-graded stigma learned about mental health at-large, the current history-graded stigma of being Muslim in America, and the stigma of various non-normative experiences compound to create crucial psychological barriers that limit one from even considering seeking care. Even when one is able to overcome these challenges, there are additional barriers related to accessing, receiving, and utilizing care.

Since the Muslim-American community offers a microcosm similar to the broad demographic composition of America, this study can help us recognize the ways we can create a more inclusive and seamless approach to mental health. To dismantle stigma, we must take a multipronged, coordinated approach to streamline awareness and education via:

1. ORGANIZING & BUILDING A COORDINATED MENTAL HEALTH NETWORK

The Background Chapter discussed the faulty mental health system and how the process of deinstitutionalization become trans-institutionalization. I am not advocating for institutionalization of individuals, but rather for an institution that can serve as the leader for awareness, research, education, *and* care of mental health. The current mental health "system" is anything but a system-uncoordinated, inefficient, and lacks holistic and integrated biopsychosocial approaches to care.

Right now, many individuals who attempt to seek treatment for themselves or their loved ones, oftentimes do not even know where to begin. My participants discussed the difficulty in finding mental health resources both online and offline. With the fear of being stigmatized they avoided asking other individuals for help on how to seek services. Instead they turned to searching for answers online but there they also found it difficult to discern legitimate sources and instead turned to networks like social media rather than even attempting to "wade through pages of psychology today" to access professional services. Organizations like NAMI, NIMH, and MHA popped up as leading mental health organizations, but none actually provide care. Individuals discussed that having to conduct enormous amounts of independent research and then having to call multiple providers to try to get ahold of someone who would be a fit or take their insurance or so on, was an extremely exhausting process.

Yet, when they had to seek services for physical ailments they knew exactly where to go and how to get help. For something like cancer care the names of go-to institutions easily came to mind and evoked positive emotions. Participants grew up collecting quarters to help the children at St. Jude's, MD Anderson, and Memorial Sloan Kettering but this has never been the case for a mental health institution.

There needs to be a top go-to institution which believes in, builds, and brands itself with a compassionate, non-judgmental, and patient-centered model can help create much needed innovation in the mental health sector. Such an institution can work to create better direction and oversight of mental health services by integrating with formal local mental health centers and informal community-based services, and also partner with existing and established general hospitals to develop comprehensive mental health services and limit the expansion of new mental hospitals.

By providing effective leadership and governance for mental health while also providing coordinated services, the go-to institution can work to develop truly constitute individualized and effective solutions and therapies for various populations. Through conducting research, planning, and investing in human-centered, best-practice implementation strategies for both the promotion of mental health and the prevention of illness, a leading institution can help consistently and efficiently track health outcomes for mental illness and improve the overall

decision-making regarding mental health across the entire country.

2. REMOVE FINANCIAL BARRIERS TO CARE

Many of my participants believed that accessing mental health support can only be done through pricey, private services. While this is not always the case, it is often the case. Some providers simply do not accept insurance and other forms of care like intensive treatment can occur significant costs- dilemmas such as these force individuals to choose between physiological necessities or mental health services. For those without insurance, seeking free of cost care, public services tend to be underfunded and understaffed.

Although the law now requires medical insurers to provide behavioral and mental healthcare coverage, there is limited coverage. Insurance may pick and choose which services they cover (individual therapy, inpatient treatment, intensive community services, etc.) and with few types of treatment specialties and restricted number of sessions which oftentimes leads to inconsistent and/or inadequate treatment. Even with "good" insurance when an individual requires consistent and regular therapy, and/or daily medications, the costs of copays and deductibles add up significantly.

To remove financial burdens there needs to be an organized front on policies at local, state, and national levels advocating for more funding for public services. As a society we need to consider how much mental health burden costs us and we need to leverage more innovative ways to bring in

additional capital to build programs that support patients and providers alike.

3. INCREASE NUMBER OF CULTURALLY COMPETENT PROVIDERS

For both public and private services alike, there are various hurdles to access providers. Since there is inadequate reimbursement from the government and private insurance plans, fewer health care providers are choosing mental health specialties. The Health Resources and Services Administration notes that 89.3 million Americans live in federally designated Mental Health Professional Shortage Areas. This is in comparison to the 55.3 million Americans who live in primary-care shortage areas, and 44.6 million live in dental health shortage areas. Some of the reasons why there is such a large shortage of mental health providers is because many rural locations have very few, if any, mental healthcare providers at all and urban settings have extremely long waiting lists.

Mental health care systems need not just add more providers but must also change how care is provided. Since many individuals who need care will not receive any care, we need to think in more innovative ways on how to incorporate care. There is currently a wide disconnect between mental/behavioral health systems and primary health systems.

Yet, since individuals are comfortable and knowledgeable about seeking care for physical ailments, I think we can create a more strengthened overall health system by integrating mental health care into primary care settings. Primary care practices are the places where patients most often interact with the

health care system. If we can increase the numbers of front-line practitioners and train them in culturally appropriate mental health screening processes, we can utilize primary care providers to help flag and triage patients for further evaluation and care by mental health specialists- building a collaborative care model.

However, building better, culturally appropriate and relevant screening processes will be essential to this effort. Participants discussed they do not want to see care providers simply to be "numbed out on medication" and will be hesitant to share concerns if the environment is uncomfortable. To create and implement truly interdisciplinary programs, provider education also needs to shift.

As discussed in previous chapters, traditional training programs in mental health do not take into account complementary and alternative approaches and vice versa. For mental health specialists and primary care providers alike, there needs to be awareness, education, and training programs that foster cross-cultural and interdisciplinary practices and cooperation across all types of organizations aiming to improve health.

Another approach to consider after the training of primary healthcare providers is incorporating other types of frontline practitioners in fields such as education, who will likely be interacting with individuals on a consistent basis and can also serve as initial points of triage to health systems.

4. RAPID & CONTINOUS INTEGRATION OF MIXED-METHODS RESEARCH INTO PRACTICE

As research in mental health takes place, we need to have an open call for a more extensive and diverse research agenda that incorporates healing methods besides traditional western medicine and biomedicalization. As precision medicine expands, we need to utilize it in the mental health space and examine approaches that are both multifaceted and individually tailored. Evidence-based practices of the future can look to encompass treatment modalities that take in ethnicity, culture, family history, genetic and biological makeup along with other factors that can truly help to follow the pathogenesis of mental illness. We need to incorporate both quantitative and qualitative measures outcome measures and while there are various qualitative and quantitative studies regarding mental health- it tends to be a long and tedious process before research is utilized in practice.

As the standard of care evolves, most providers don't adopt quickly enough and there is room to build a research tool that collects, aggregates, and compares both individual and collective provider clinical decision-making data instantaneously. This type of innovative research that is driven by software analysis could help providers examine dynamic real-time relationships between symptoms, treatment variables, and interactions between treatment modalities to understand their decision-making. In turn this will help them make the most effective treatment recommendations for their patients/clients based, like what

types of treatments need to be integrated, what needs to be changed, etc. and over time lead to the best health outcomes for patients.

For example, if a qualitative research study finds that patients do not trust the PHQ-9 and lie when answering questions, then providers could ask patients if they feel comfortable answering the PHQ-9, and why. If many patients respond that they did not feel comfortable answering the questionnaire, this data can help providers understand if PHQ-9 data is accurate or it can lead them towards developing new screening methods for psychological distress.

A current quantitative challenge that providers face is with prescribing the right medication and the correct dosing. Usually, it takes several tries, with a wait time of several weeks and this can be a frustrating process for patients and providers alive. When multiple providers across the country are inputting their clinical decision-making data about medications and dosing, along with more unique patient symptoms or behaviors- data can be aggregated, fine-tuned, and then utilized to find the best fit solution. For example, if two patients are exactly the same physiologically but have had different prescriptions for the same diagnosis previously, how those experiences will pan out can then be recorded and used to help the third patient in the future.

Research findings and results can help us eventually determine the complex interrelationships between the symptoms individuals experience, their responses to treatment, and the positive feedback loops between lifestyle behaviors and outcomes. Research can help adjust needed lifestyle modifications

like changes in diet and exercise, mindfulness meditation and mind-body practices. Additionally, it can also help patients determine alternative solutions and supplements that might be beneficial and how they can be safely combined with pharmacologic and psychotherapeutic interventions. All of this can help create a culture change where holistic approaches can then easily be incorporated into mainstream mental health models of care.

It can find the discrepancies between different treatment variables that might otherwise be missed without the use of such software in traditional research studies. Having a continuous stream of research and the ability to constantly re-evaluate and individualize treatment could help us in creating new standards of care for mental health not just through the lens of biomedicalization but alongside an array of social/cultural lens.

There is hope that precision medicine and artificial intelligence can provide us with a wealth of data that helps us ascribe and embody the philosophy of whole-person care, focusing on the total health of patients. Better translation of research into clinical applications can help improve the operational and delivery components leading to more coordinated efforts and improvements in care delivery. They can help us coordinate the biological, social, cultural, and spiritual dimensions of mental health.

5. UTILIZATION OF NEW & EMERGING TECHNOLOGIES

Along with the research software idea mentioned above, there can be many other flexible and innovative technology-based tools that can work to expand the reach, efficiency, and efficacy of providers and treatment solutions. For example, software-based telehealth and automated CBT are just a few of the tools that are creating new types of healthcare infrastructure which will increase access to services in places and situations where there is a lack of mental health providers. Other tools are emerging that focus on psychoeducation and self-care, along with more formalized web-based educational programs that are working to train future integrative mental health providers.

* * *

This study shows that Muslim-Americans interstitial identity, compounded by socio-political and religious-cultural and frameworks, impacts their perceptions of and attitudes towards mental health. While I was not able to seek out all types of diversity within the Muslim-American community, this small group's demographic reflection does make an attempt in showcasing parallelism with American society at-large. My purpose was to bring to light that mainstream American narratives of mental health care and support do not adequately accommodate varying approaches to personhood and well-being.

My suggestions to dismantle stigma from various points of access but primarily through the notion of developing and streamlining coordinated efforts for awareness and

education through first organizing & building a coordinated mental health network, second removing financial barriers to care, third increasing the number of culturally competent providers, fourth rapidly and continuously integrating mixed-methods research into mental healthcare practices; and fifth utilizing new & emerging technologies in productive and positive ways to make an impact on lives.

My work was focused on Muslim-Americans but I hope this works leads to health justice for all communities who are in need of it, and that we are able to building capacity to reach those that need it most, regardless of their religious background, social status, or any other identifier, I believe can all play a role in helping develop a collaborative model of care that is stigma free, invokes positive perspectives around mental health, is less costly, safer, and more effective for everyone who seeks help. I hope this study can help guide policy, research, and innovation in mental health that thinks about wellness, prevention, and treatment of mental health in unified ways. Most of all I hope that it can lead to better design of the mental health system and help uplift all populations, increase patient engagement and satisfaction, and ultimately improve health outcomes for those who have suffered with mental illness for so long.

While I believe that at times our beliefs can muddle our neutrality and impact which research data we select and use, which data we leave out, and how we interpret that data- I also believe that for this study it was important to bring my own perspective. I began this work for my own healing, honestly seeking a simple fix to take my mental illness away. While I found no such thing, I did find my voice. I learned how to advocate for myself and for others, I learned how to think critically and how to find meaning and

purpose even in moments of deep despair. I learned to keep going, I have learned to believe that things can get better, and I now know how to work towards making it so.

It has not been an easy road, I have struggles with major depression for many years and it has taken me much longer than my peers to accomplish the things I have sought. But I have learned to embrace the journey and know that my journey is my own and it does not need to be in comparison to anyone else to have found success.

For success is different for all of us, and it changes over time. Some days success is simply being able to get out of bed, or swallowing a bite to eat, other days it looks like finishing a 5k race or finally being able to graduate.

I shared these stories, those of my participants and part of my own, so that they can be of aid to those who are also struggling. I know that sometimes it is simply the act of caring, be it from a hug, a phone, or a book, which can make all the difference.

Thank you for taking the time to read through this thesis. I hope it has done some good.

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